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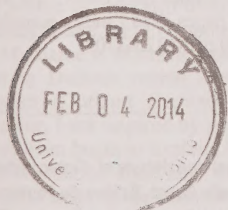
Lundi 13 janvier 2014

Select Committee on Developmental Services

Developmental services strategy

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Stratégie de services
aux personnes ayant
une déficience intellectuelle



Chair: Laura Albanese
Clerk: Trevor Day

Présidente : Laura Albanese
Greffier : Trevor Day

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**SELECT COMMITTEE ON
DEVELOPMENTAL SERVICES****COMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE**

Monday 13 January 2014

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The committee met at 0903 in the Delta London Armouries Hotel, London.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Well, good morning, everyone. I give a welcome to all the members to London, where we start our week of public hearings for the Select Committee on Developmental Services. Welcome to all of you.

I wanted to mention that the coffee is up here, but you are more than welcome to come up and have coffee or tea, if you wish.

**PARTICIPATION HOUSE PROJECT
(DURHAM REGION)**

The Chair (Mrs. Laura Albanese): Having said that, we'll move directly to the first presenter, Michelle Marshall, executive director of the Participation House Project of Durham region. Welcome. As you're taking your seat, I will specify that you'll have up to 20 minutes for your presentation. Should there be any time left over after your presentation, that will leave room for questioning by the members of the different parties. When you begin, if you could please state your name and title, just for the purposes of Hansard. You may begin at any time.

Ms. Michelle Marshall: Great. Thank you very much. Good morning, respected members of the panel and guests here today. Thank you for providing me with this opportunity to speak before you and to provide insight that might help to address some of the critical issues that are before us, and also to explore how we might shape a healthy future for developmental services.

My name is Michelle Marshall and I run an organization in Durham region named the Participation House Project (Durham Region). In the role of executive director, I am inspired by people every day in ways that I can't even begin to explain, but this in good part is due to the wonderful staff and volunteers that dedicate their skills to helping the community, the leaders and direction of a selected few, and the commitment of all to doing things differently, not for the sake of just doing it differently, but because we're on the endless mission to do things better.

In the spirit of doing things differently, what you have in front of you this morning is my presentation that's a little bit different than probably what you're used to seeing; that's for you to read later. I'll cover everything within it. But our organization is inherently collaborative and I wanted to provide you the opportunity to contribute to the discussions as much as I do, so my plan is to leave a lot of time for questions where we can talk through the different points of this morning.

Here's what we're going to talk about:

I think that, first and foremost, it's important that I'm able to demonstrate to the committee that Participation House Project is a progressive innovator that does not shy away from changes and prides itself as a provider of environments that promote continuous learning and as a provider of quality services.

With the recent relocation of our administrative office, we sought out partners to share space with us to minimize our administrative costs, but with a view to providing a centralized access point within an accessible community-based facility of high visibility. We share our administrative space with the DSO of Central East Region, the regional children's complex special needs service coordinator, and also the Passport delivery agent, all with a view of making services easier to access for families in Durham region.

By now you've heard from many organizations and families about the dire situations that grow within the developmental disability community. As an accredited organization, the Participation House Project, Durham region, has risen to the challenges that have been put before us and we've found new ways to deliver services that build capacity while maintaining the quality in our service delivery. Over the past five years, and since the time of the funding freeze, we've been able to expand our services in the community access supports by approximately 35% through the introduction of a blending of publicly funded services and fee for services or grant applications.

However, having said that, creativity has not been the only factor that has enabled us to do this work. By and large, our commitment to provide transparency and partnership with our employees has played a very pivotal role. Our employees have also ensured that we all play a role in ensuring financial sustainability of the organization. We have done this with three priorities that have

guided us in our decisions. The first is that we always want to find ways to maintain our current positions and the services that we provide. We want to maintain the quality of our services as we expand them. And we want to make sure that we maintain our ability to continue to be responsive to our community's needs.

Through a collaborative team approach, we meet regularly to find ways to cut costs, neutralize our costs, or create new revenue from existing resources.

I provide you this preview of our track record to preface my comments when I say that despite all of these good efforts and commitments, we now find ourselves at a critical crossroads where the hard work of our team may be compromised if something doesn't give.

Durham region is one of four quadrants that used to be part of Central East Region. As you probably are aware, through the realignment it changed as of January 1. Historically, Central East Region has been a very progressive region. We've provided much leadership for the province through the establishment of centralized regional resources such as the Community Networks of Specialized Care and regional complex special needs coordination services. By and large, we've been very successful in the implementation of these excellent models of services, and it's been through a collaborative planning table known as Central East Planning. This committee is comprised of partnerships between MCSS regional office and representatives from the four quadrant planning tables and from the regional resources. Together we've been able to successfully implement and help transition our community of practice into a blending; with the introduction of new initiatives such as the DSO, we've been able to maximize our resources with minimal duplication, and all with the commitment to do the best and most with the limited resources we have.

I am proud to have been appointed as the chair of the regional planning table, but now I'm fearing what planning might look like within the new realities of a new region. You see, Central East Region is the only region that was divided in half when the ministry recently announced their realignment from nine to five regions.

0910

In reference to correspondence that was circulated to announce this realignment, I know that the intention was not to impact families or direct services, but this is not the reality. Sadly, when the decision was made based on the math of how many people were being served and the number of people waiting, the realities of the community within Central East were overlooked. So through this division of all regional offices, the regional resources will be taken away from Durham, Peterborough, Haliburton, Kawartha Lakes and Northumberland because the current regional resources are housed in agencies within York and Simcoe regions.

As a community, we made a commitment to use our funds wisely when we created regional resources, but now these efforts and commitments have been undermined unintentionally, and our families and our communities will suffer. During a time when organizations

are already feeling stretched, the leaders of these transfer payment agencies in Durham and in HKPR will not only have to learn new processes, new planners and procedures, they will also be taxed with the financial costs that are related to retraining our staff, our community and our partners, and reprinting of all brochures and policies and procedures, to name but a few.

In my submission to you, I have provided you with some statistics to help place a face to the needs of the Durham community and Central East Region. Currently, within Durham region, the waiting list would look like this: group homes, 551 people waiting; supported independent living, 283 people waiting; associate family, 113 people; day supports, 331; and respite services, 267. Specifically for Central East Region, group home is 1,260; supported independent living is 359; associate families, 234; and non-specified requests, 794. These are all non-duplicated numbers that were effective as of December 31, so they're very current.

Although I've provided you with a focus to the needs of Durham and Central East Region specifically, it's not that I'm unaware of or that I'm in disagreement with what has been presented as the provincial challenges. Moreover, it's to provide a local face to the critical provincial issues that my colleagues and the families who presented before me have highlighted to you.

So where do we go from here? In review of the transcripts of the presenters that came before me and the questions that have been put forward from all of you to them, I'll attempt to proceed where things left off and to provide some additional insights. I'm not a doom and gloom kind of person, and I refuse to lose hope. Despite all the obstacles I've just shared with you, here's what I think we should do.

I have read discussions and have heard inquiries that have asked for guidance and have asked us to identify short-, medium- and long-term interventions. The truth of the matter is that if we continue to respond in a way that prioritizes one person's needs or the most in need over another person's, we're just perpetuating the core issues that the transformation agenda was put in place to overcome. It's a travesty, really, that families and individuals have to reach crisis before they receive supports, and this has to change right now.

When we take an inventory of the needs and the characteristics of people who are currently on the waiting lists for services, we can quickly identify that we have two key audiences and motivations for necessity of service access. We have those who have languished on waiting lists for often greater than 15 to 20 years and whose life experiences and choices were very different than those of the people of today. The societal values and the strides of inclusivity were not their reality. They were robbed of options and supports that would have prepared them to be ready for the realities of a future system that doesn't follow a 24-hour model. To further compound their situations, because these individuals and their families have been isolated from their communities and having access to preventative or proactive supports, their support needs

when they do engage with agencies are usually much more complex and much more expensive. And usually, other needs are much more immediate.

The other target audience that I would identify are those who have had different experiences: those who are well-informed of their rights and are poised and prepared to transition from school into adult life. As a community, we've taken more responsibility in playing a role that empowers these individuals and has prepared them for independence and self-actualization. However, if these young adults are left to waiting lists for services, then these skills, too, will be lost.

We cannot continue as a system based solely on "most in need." We must stop the dysfunctional cycle that violates the rights of Ontario's most vulnerable citizens. This is why I'm suggesting that we need to take a two-pronged approach when addressing the immediate needs of today. We cannot begin to plan for tomorrow without getting our house in order. So what I'm suggesting is that we look at critical immediate needs—that would be looking at increases to case management, residential supports, day services and respite, while at the same time looking at providing proactive and preventative approaches that empower individuals and keep families from going into crisis, and that's in the areas of respite, life skills, training, case management and employment supports.

We cannot begin to plan for tomorrow without getting our house in order. Moreover, I have faith that tomorrow will be looked after through the leadership that the AODA language and the transformation agenda will bring.

I'd like to thank you, again, for providing me the opportunity to speak before you today, and I'd like to give you the opportunity to ask me questions about what I've provided to you.

The Chair (Mrs. Laura Albanese): Thank you. I think we have about two and a half minutes for each party. Ms. Elliott, you may begin.

Mrs. Christine Elliott: Thank you very much and good morning, Michelle. I have the pleasure of knowing Michelle quite well and knowing the great work that she does in our community.

I'm wondering if you could just spend a few minutes, Michelle, talking a little bit about the supports that Participation House does provide in the community and some of the things that you're working on, as well, to address the needs, particularly of young adults with autism.

Ms. Michelle Marshall: Sure. Thank you for the opportunity. Participation House provides a spectrum of services from residential to respite, as well as community access and day supports. We provide them in a community-based situation, but we've also largely tried to find ways to partner to prevent duplication of services.

Over the last few years, we have partnered with the Abilities Centre to create and expand our supports and, again, to make them much more accessible to individuals in our community and within a community fully-

accessible environment. We've been able to do that by bringing our services, that we previously had provided to only funded individuals, to a community resource centre, where they can access other programs and services. So where once we may have supported, say, 10 people, we now support two groups of five, which has reduced the costs for other people to purchase services. So we have been able to provide it more cost-effectively to families while expanding our services.

There are some challenges with that, because under the new DSO legislation, any of those vacancies, because there is partial funding by ministry—it does have to go through the waiting lists. Of course it has to then go through, trying to find the match and being able to partner families into those resources. It cannot be done as quickly as it has been in the past. That's something that's happened more recently, as day services have been something that now are overseen by the DSO.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: Yes. Thank you very much for your presentation. Obviously, what we've heard from you, we've, in a sense, heard from others.

You talked about the two-pronged approach to redressing problems. So I'd like you to go a little step further maybe and say what's necessary to achieve that two-pronged approach. Is it money? Is it changes to the DSO? Maybe you could—

Ms. Michelle Marshall: Sure. I think, at the end of the day, it's money. I think it's fair to say that. We all own our own homes; if we don't invest in preventative maintenance, the reality is, you're going to be replacing your roof. You're going to have a big bill. I think we're in that situation, because for so long there hasn't been adequate funding to meet the needs. The needs have continued to grow, and there have been no new resources.

A lot of the resources that we've seen as of late have been to infrastructures, such as the DSO, and to other processes, as well as providing dollars for training. I think it's all been with the view that it's going to build some more capacity, but, really, what we've got, at the end of the day, is someone saying, "Here's the end of the line," with no new services.

So we're at a point where there do need to be resources specifically for services, but what we've seen is, when we talk about doing training and providing employment and respite, those are all band-aid services. As you all know, the reason we're here today is because we're at a critical crossroads within the sector. This is just a band-aid solution, and it's actually not going to be able to help the people who are most in need, and they will continue to rise to the top and will be the people who keep you awake at night. So I think that we need to make some serious investments.

0920

Yes, we're right: We need to look at employment and respite for those individuals that I identified as, really, they're ready and they're poised. We want to make sure

that we empower them so they're less reliant on 24-hour services, because truly, if we're going to build capacity in the future, we need to better prepare people so they're not looking for those 24-hour models. But if we do that in isolation, we are going to continue to have these families that come forward in a critical, crisis situation where there are not the adequate resources to respond. These are generally individuals, at the time they entered the waiting list, who were looking for 24-hour models. As they remained at home and isolated from services and other supports, any skills that they might have had as they exited the services of entitlement for children have been lost. There might have actually been more health-related issues as well that have compounded it.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter?

Ms. Mitzie Hunter: Thank you, Ms. Marshall, for your presentation and certainly for the effort that you've put into preparing this for us. We will definitely include it in our report-writing considerations.

I know that you have a little bit of concern around the changes in the regional model. I do want to assure you that the intention there is to streamline across ministries, based on the regional models that we have for ministries, and that there is no impact on the public, there are no offices that will be closed, and the public will continue to interact as they do. We are in the early stages of that, and we'll be working together to ensure that there is that seamless transition. It really is intended to streamline and to make it consistent with other ministry processes across governments.

Also, in the area of transitioning and working better with our Ministry of Community and Social Services and the Ministry of Children and Youth Services, particularly for this client group, you've also expressed some concerns there as well, and we've certainly heard that as we've been listening to others during the course of our hearings.

I'm wondering, with the work that you're doing in the community, how do you see making services and supports available in a much more integrative way across the communities? Is that something that you're seeing, that we need to develop a better culture of inclusion of people with developmental disabilities, and is that something that you can comment on for us today?

Ms. Michelle Marshall: Sure. I think that, culturally, there has been a huge shift in the sector for many years. This isn't something new because it has been put into legislation. If anything, the legislation has been put in place after, to support those of us who were trying to make strides, and also to ensure that we create a groundswell.

I think that we're on the right track and taking steps forward in expanding our communities and also their awareness of their responsibilities to helping being part of the solutions, because if we truly want inclusivity, we need to make sure that everyone understands what their role is in it and that it isn't only under the Ministry of Community and Social Services or Children and Youth

Services. It needs to be a full-community approach to that.

As far as the challenges within our community, I think that I understand what you're saying. Certainly, I can appreciate, and did address that I know the intentions of the realignment were not to disrupt services. But specifically within Central East, because we are the only region that is being divided in half, at the time that we receive resources, rather than dividing those and saying, "Well, you have four quadrants; we'll divide that by four. Go away into your quads"—we wanted to make sure, because we understood that there were exceptionalities that needed very specific resources. But to put those in place and have quality that we could provide to people of that high level of need, we needed to be able to centralize our resources, and that's what we did.

It is unfortunate, though, for the people of Durham region and HKPR, because all of those resources are now within Simcoe and York and they're being divided and taken to another region. For our families, it will mean loss of services, because there may be things in other communities but they're not going to be the same.

I do believe, and what I've heard, is that we've been very progressive as a region. We have a really great community planning table that has been very diligent in making sure that we use our dollars wisely and that we make sure that we're being responsive to community needs. Those were created, centralized, for really the full spectrum of needs within the four quadrants, and those are being taken away from us. I do have to have faith and hope, though, that through our planning table we'll be able to continue to communicate what those challenges look like so that we can work through some transition. However, I think it's of importance that we can't put our heads into the sand. We need to be aware and we need to address that head-on as a priority because, like I said, this is one region and this is not going to be the same experience as that of the other regions that are being realigned.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us this morning. You may be free to go. Thank you.

Mrs. Christine Elliott: Some of us aren't as familiar with the realignment that Ms. Marshall was speaking about. I wonder if our representative from MCSS might be able to give us a briefing at some point about when that was done and for what reason. Would that be possible?

The Chair (Mrs. Laura Albanese): Okay, thank you. We will put that in our agenda during the week.

MS. SUSAN BURO HAMM

The Chair (Mrs. Laura Albanese): We now call on Susan Buro Hamm to come forward. Good morning, and welcome to our committee. I believe you were present when I gave instructions, so you know you'll have 20 minutes. If there's time left over, we will delve into questions. You may begin at any time.

Ms. Susan Buro Hamm: At the core of Canadian beliefs lies socialism. One of its tenets is to protect and take care of those most vulnerable. Yet here we have Ontario failing miserably those young adults with developmental disabilities. It has been hopeless, bleak and absolutely shameful. The time for change is today, and the solution lies in listening to those most affected, such as my family.

My name is Susan Buro Hamm. I'm from St. Thomas, Ontario, in Elgin county. My husband, Abe, and I have four beautiful girls: We have Lexi, who is 20; twins, who are six; and a wee foster daughter, who is three months old. Lexi has epilepsy, metabolic disease, mild CP, and is globally developmentally disabled. There is no umbrella or syndrome for Lexi to coattail on to—just a lot of puzzle pieces that don't quite fit. In 2010, Lexi was the victim of a horrific bullying incident. She was assaulted on a school bus. It was videotaped and it was posted to YouTube. Since that day, Lexi has developed severe mental health issues. It's the mental health issues and her complex medical needs that have brought us to crisis, time and time again. Having a dual diagnosis is a very challenging entity in its treatment and in a family environment.

Let's talk about crisis for a moment. I often talk about Lexi in terms of crisis, but people forget that there are four other family members who are greatly affected by her illness. There's a toll on my marriage, on our finances, on our other children and on our extended family. So let me tell you about crisis for a minute; I'm going to tell you what it looks like for my family. When Lexi turned 18, in one fell swoop we lost our pediatrician, our family support worker and our respite. We then had to enter into the foray of adult developmental services under Developmental Services Ontario—I'm going to refer to that as DSO from now on. What an experience that has been. First we are required to prove that our child is indeed developmentally disabled, as if the prior 18 years of ACSD, assessments at CPRI, numerous specialists and special education were all for naught. I don't understand how the government, in its infinite wisdom, could not just cross-reference and easily see that she indeed was handicapped.

At Developmental Services Ontario, you have to have an invasive in-home assessment. Our assessment was 10 hours long, spread over three days. We then waited for a report on the assessment. Then the report is passed along to a mysterious priority panel who prioritizes what level of priority your child sits at. What happens then? Action? No. You're placed on waiting lists for any type of services you might need: residential, job training, recreational, specialized mental health care—anything you need, you wait for. So I know she's on wait-lists, but I have no documentation to tell me what specific wait-lists she is on, where she is on the wait-lists, and no updated information. I've asked for documentation and have been denied this request. There's no way I can appeal any process at the DSO. There's no appeal process and there's no tribunal committee. When you go to ODSP

and there's a difficulty, you're always able to go to a tribunal committee. There's nothing at the DSO. You have no way of getting your message across. There's no way to be heard, and I find that the lack of transparency is very painful. I've come to believe that the DSO is simply a manufacturer of wait-lists. It serves no other purpose.

0930

The thing about crisis is that it waits for no reports and no assessments. All of us fluctuate and change in the blink of an eye; people with a myriad of complex needs, as well, their needs can change in the blink of an eye.

The DSO process took months, and in those months, Lexi became much sicker. So my child has severe mental health issues, and due to her illness, her cognitive functioning has dropped significantly. The original assessment we had done at the DSO is now null and void because of her illness, so we have to do the process all over again, only this time, there's a big backlog to send the assessments on to the priority panel. So I'm on a waiting list to get on the waiting lists. That's ironic.

In February 2013, Lexi became sicker. I called the DSO on a regular, daily basis, updating each and every excruciating detail of Lexi's illness. The thing about accessing resources is that you have to be brutally honest with yourself and every service provider you encounter. Our lives are wide open. I will not hide behind any stigma. Lexi was suicidal, psychotic, running into traffic on our busy street, banging her head, uncontrollable rages—she was incredibly ill. Nothing was done for us at the DSO level—nothing.

We went to Community Living Elgin and they provided us with emergency funds. My family and another local family ate up the entire emergency fund in Elgin county—two families. We were able to work with Community Living, and they were able to provide short-term, temporary respite. Respite is crucial to our family. It allows us to breathe, to regroup and to focus on our other children. It cost our family \$2,300 for a weekend of respite—\$2,300; it's way more than our mortgage payment.

Those emergency funds lasted a short four months. In those four months, Lexi became even sicker. It was a sad time in our lives. We truly needed a worker in our home every waking hour to keep Lexi stable and secure and to protect our family. The DSO was aware of this. The Ombudsman had taken on our case. Jeff Yurek, our local MPP, was incredibly supportive. Yet there was nothing in our rural county: There are no emergency beds, no centre-based crisis intervention, no respite. There was only hopelessness.

Our crisis reached an all-time high when I became ill and I required surgery myself. Lexi was then hospitalized at Regional Mental Health here in London. I nearly died. I needed a second surgery. Imagine this: I'm her main caretaker, her unpaid case manager, her advocate, her support system, and I could not do a damn thing.

It was monumental, a massive crisis in our family. My husband was caretaking our younger children and attend-

ing to me. He's Lexi's stepfather, and while he loves her immensely, I'm her main caretaker. I called the DSO from my hospital bed, begging for help. An upper-level manager told me to abandon her to the hospital and that they would deal with her. As well, as I'm begging and pleading for a group home placement, the upper-level manager coldly said to me, "As of 12:36 today, no one has died to provide your child a bed in a home"—so utterly callous.

You might ask where my family was in all of this. My parents and my in-laws are aging. They have medical needs of their own. Two years ago, my mom fell and broke her leg, had a heart attack, and she moved in with us. I took care of her for six months. Last year, my in-laws were involved in a serious car accident, and they're healing from their injuries. So family members that used to be able to provide support are no longer able to. Our support system has shrunk.

I am one of the sandwich generation: I am actively caretaking my immediate family and my aging parents as well.

For 20 years, I've been a strong advocate for Lexi, always seeking resources for her and other community members. I've met every new challenge with determination and courage, and rarely take time to feel sorry for myself. I co-facilitate a parent support group in our county. I am Lexi's case manager. I receive no pay for this incredible amount of work that I do. I cannot work, as employers are not very sympathetic about our constant crisis. I spend hours on the phone or at meetings, pleading our case. If I don't understand, I ask questions until I do understand. I keep pushing and annoying the heck out of agencies and, I'm sure, government offices as well. I owe it to Lexi. I take my role as a parent very seriously. I am virtually helpless these days because I'm unable to access services that will help my child get better, to thrive, to be successful and to have a fulfilling life. The wait-lists seem insurmountable. We become more mired in crisis from our inability to access those services.

Lexi graduates in June; she is done high school. What becomes of her? There is no longer any transition planning in our community—none. There are no job training programs. Day programs cost anywhere from \$50 to \$200 a day. There are only wait-lists. She deserves to have a fulfilled life like any other 20-year-old but needs daily supports to accomplish that. Her most basic human rights are trampled on.

So let's talk about solutions. You've heard about our crisis and what it looks like for our family. Let's take a few minutes and talk about solutions. The first step in solving a problem is admitting it's broken. Services for adults with developmental disabilities do not exist, except on paper. They are only empty words and false information. The MCSS website talks about services for adults with developmental disabilities. It should have the following disclaimer on it: "Caution: While in theory everyone receives these services, at this time there are only wait-lists available."

You cannot misinform parents or consumers any longer. You have to admit there's a massive failure and start fixing it. It is only going to get worse in the years to come. Trust me; there are parents coming up the line who are going to lose their funding with their children at 18, and they're already mad. Do not lay blame; do not analyze it; fix it. We need long-term, sustainable solutions, with various ministries working together to share costs and funding. We need to be innovative in our solutions. Combinations of formal and informal supports are what have been successful worldwide. If I hear one more government official say to me, "Experts say," I truly am going to vomit, because I am the expert. I live it 24 hours a day, every single day. Twenty years of experience I have; 20 long years. So ask me. Utilize my experience. Don't tell me what I need. Listen to my voice. Hear me. I'm more than willing to help. I'm more than willing to do my share. I'm willing to offer up solutions and to work with you.

We need rural solutions, not just urban solutions. In Elgin county 10 years ago, there was no wait-list for residential placement. Today, that list has grown to 114 people. We need local resolutions in our community such as housing, psychiatric services for dual diagnosis, crisis beds, and respite funding.

Our most immediate need is housing—safe, supported housing. Other parents and myself have formed a non-profit business called Elgin Active Living. We want to buy a local closed school and turn it into apartments for adults with special needs. We have partnered with another non-profit business that runs a phenomenal day program. This business will purchase space in our building and will run the day programs and provide staffing to our apartments. We will have a community centre attached as well. We will have enough land to provide job opportunities for our clients such as gardening, a café, a bookstore and a pet-sitting service. We have tried innovatively to find a solution to our problems, but the reality of this dream is a difficult one. Each family in our group has suffered a major crisis in the last year. There is hope in innovation and partnership, and the government needs to partner with groups such as ours.

We need more immediate crisis intervention for those with a dual diagnosis. It is an area that needs more funding, more research and more time than I can give it today. While dual diagnosis falls under CMHA's mandate, it is still not given enough emphasis in the world of mental illness.

I leave you today with one last thought. It's not a pretty one; it's harsh and stark and it haunts many of us as parents. I understand why parents are forced to abandon their adult children. It's not because they're cold or callous; it's because their hearts are broken and their spirits are crushed by years of traumas, crises, endless paperwork, and meetings upon meetings with teachers, principals, doctors and specialists. We have health problems ourselves that develop from years of stress and crisis. We are aging, and that in itself leads to health difficulties. We have government edicts that change with

no thought or research into how those edicts affect our families in the long run.

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I'm one of those parents who has lain awake at night wondering if the next crisis will lead us down the road to abandonment, and that is a horrible, horrible thing to have to face as a parent.

So today, I call to you out of the darkness that is the stark reality of adult developmental services. I hope you heard me, but most of all, I pray that you remember Lexi. Thanks.

The Chair (Mrs. Laura Albanese): Thank you for your honest and passionate presentation.

We have about two minutes for each party. Miss Taylor or Ms. DiNovo?

Ms. Cheri DiNovo: First of all, thank you for your presentation. Personally, we're horrified by what you've had to go through. It's unconscionable. I can't apologize on the government's behalf—I wish I could—but there are no words for that. You've given a wonderful presentation.

A couple of questions: You must have looked into and thought about other jurisdictions that do it better. Can you point to one? Is there a light somewhere of someplace that delivers services better than we do here?

Ms. Susan Buro Hamm: I think we're so mired in Ontario, all over, that it's hard to seek out those resolutions. When we began researching about trying to find our own solution to housing, we looked at other countries. We looked at other small projects. I believe the ministry has supported a small project in Quebec of the same type of idea that we have. It becomes their home. They have a home for adults with developmental disabilities; it's like a farm. So we began to look at these types of ideas, innovative ideas, ones that would make us feel secure as parents, that we could have control in, that we could have a say in. They're very few and far between, and we've actually sought in other countries and taken ideas.

Europe has fantastic ideas and placements of adults in homes. We did look out there but in terms of accessing services and things, most communities have their hands tied and have even greater waiting lists than Elgin county.

Ms. Cheri DiNovo: And just quickly, the DSO: What would you do with it?

Ms. Susan Buro Hamm: I'd get rid of it completely. Right now, you have people who are sitting there earning dollars and you have top-level executives and you pour all this money into staffing and offices, and they have done nothing. They have done an assessment for my child, and if I run into crisis and call: "Okay, we'll update your file." That's it. Any other services, any other thing—there's nothing. I'm not sure what the replacement would be, but it's a useless entity. It really, truly is. I've gotten nothing but an assessment and wait-lists. That's it.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter.

Ms. Mitzie Hunter: Thank you so much for coming today to appear before the committee and to share your story, and Lexi's story as well.

I have two quick questions, I hope. You talked about types of job training, and what would be helpful?

Ms. Susan Buro Hamm: For Lexi to be able to have an independent, wonderful, fulfilling life—Lexi probably has the ability to have some sort of job, not full-time, but training. So whether it be a volunteer position, whether it be a paid position, she needs a full-time worker there with her—the ability to access that quickly and efficiently.

And transition planning: They took the money that used to be at Community Living for transition planning and they gave it back to the schools, and they said the schools are now going to be doing transition planning. That doesn't exist in our school; there is no transition planner in our school. So we need transition planning to help them, because at 20 years old you're thrown out and there's nothing for her to do. She cannot be at home. That will make her mental illness—it's a crisis waiting to happen, I can tell you that. I can guarantee that.

She needs job supports. She needs immediate access to job training, and it needs to be permanent.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Jones.

Ms. Sylvia Jones: Thanks for presenting today, Susan. I am interested in learning more about one of your solutions. The Elgin Active Living Centre sounds like a pretty creative innovation for parents who are having their own challenges. I wonder if you could share with the committee: Who have you presented that to? What kind of blocks are you getting? Is it the residential mindset? Help us.

Ms. Susan Buro Hamm: It is. Most of the parents within the group have children who are going to need residential placements sooner rather than later. They're going to need incredible amounts of support. We have varying degrees of—you know, a family that has an autistic child with Down syndrome, another one that has a physically handicapped child who is in a wheelchair. So we have all kinds of different levels of care needed within it.

It's really unique in that when we began looking for a solution, we realized that, you know, we put this intense pressure on the government to provide solutions. We can work together and come up with a solution. With Elgin Active Living, we thought, "There are tons of empty schools in our area." We toured the schools. We went and looked at them and we found one that meets our needs totally. It has an incredible gym; it has open space for a day program. The classrooms are all going to be converted into accessible apartments. We're going to have a main dining area. We're going to have opportunities for our clients to have jobs, volunteer jobs, and to be an open part of the community and revitalize that area.

We've presented to Jeff Yurek; we've had a news conference; we've spoken to various groups in our community that are very, very supportive. We've talked

to schools so that parents are made aware that they are welcome to join our group.

The other thing is that it's a cost saving. We actually did a cost comparison. I'm not sure if you're aware that in a group home, depending on the level of care needed for your adults, costs can be anywhere from \$200,000 per year upwards to \$1 million, depending on the level of care needed. We've actually done it so that we pool our pot of funding and we're able to utilize—for example, Lexi doesn't quite need so much support when she's sleeping, but some of the other clients do need support. So we pool our funding and we save money that way in that we're not using the typical model of assigning—you know, "That family needs \$1 million in care." We're spreading it out so that we're able to help more families effectively.

We can fit anywhere from 12 to 16 clients in the facility. We hope to actually do it with other—we've looked at other schools and expanding. It's a model that could be used and utilized across Ontario.

Ms. Sylvia Jones: Thank you. And to that, very briefly—

The Chair (Mrs. Laura Albanese): Thank you. Sorry, the time is—no, I'm sorry.

Interjection.

The Chair (Mrs. Laura Albanese): Sorry. They didn't get that.

Ms. Sylvia Jones: The DSO manager who made that comment to you should be counselled to other employment.

The Chair (Mrs. Laura Albanese): Thank you very much for sharing your story this morning.

Ms. Susan Buro Hamm: Thank you.

CANADIAN MENTAL HEALTH ASSOCIATION WATERLOO WELLINGTON DUFFERIN

The Chair (Mrs. Laura Albanese): We'll call now on the Canadian Mental Health Association from Waterloo, Wellington and Dufferin. We have two presenters here with us this morning. Good morning. Welcome to our committee.

Ms. Adrienne Crowder: Good morning. I'm just going to introduce, and then we'll do a little bit of back and forth.

First of all, we're just really appreciative of the work you're doing. It is so important. We're very grateful we have an opportunity to share some information and hopefully help you in your decision-making.

My name is Adrienne Crowder.

Ms. Angela Allt: I'm Angela Allt.

Ms. Adrienne Crowder: We have interesting roles. We have roles called service resolution. Angela works within Waterloo and Wellington counties; I work within Wellington and Dufferin. We'll explain those roles a little more, but we have the opportunity to see cases vertically, so we see them from front-line through to either ministry or LHIN representation, and we see them

horizontally across multiple ministries, so we see social services, health and justice. From that perspective, we're going to share some of the information that impacts us in our work and that we're hoping will help your committee.

Ms. Angela Allt: Again, thank you for the opportunity to be here this morning. We are both very appreciative of it.

I'm the service resolution facilitator for Waterloo and Wellington for adult mental health and addictions. But part of my caseload is comprised of individuals who are dually diagnosed, and those are the folks I'll be focusing on this morning.

In my role, I'm tasked with finding supports and services for the most complex and difficult-to-serve individuals in the region. People are referred to service resolution when a primary support or community partner cannot access appropriate services and/or are experiencing difficulty in supporting the person.

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In reference to the dually diagnosed in our region, my role could include things such as advocating for support coordination, advocating for admission to in-patient services, assisting with sourcing and referral to outpatient expertise, and working amongst community partners, including mental health agencies, developmental agencies, police, probation, hospital and housing providers, to come up with a plan to support the person. I assist in finding housing for people with very challenging behaviours and/or complex needs, and I participate in system-level initiatives that develop increased capacity to support people, such as a program specific to our region, the Extraordinary Needs Program, which funds a variety of extra supports to enable people who are in hospital to be discharged to the community, people who would otherwise have to continue to stay in the hospital.

In the adult mental health and addictions service resolution stream, those with a dual diagnosis generally make up approximately 20% to 25% of my caseload at any given time. The amount of time and effort put into managing and resolving their challenges, as compared to other individuals on my caseload, is much higher due to the nature of their difficulties.

In 2013, both streams of service resolution, as represented here this morning, undertook an examination of the consequences and costs of the lack of comprehensive service planning for those identified as being dually diagnosed. An overview paper was produced that looked at the service usage of just five individuals in Wellington county over the course of a year, and we have made that available to you. It was discovered that seven different hospitals were accessed. Two correctional facilities, two police services, probation services, and 10 community-based mental health and/or developmental service providers were involved with the clients at multiple points in time. A breakdown of the individual usage of services, as reported, can be found in the accompanying handout.

What can be surmised from even the briefest examinations is that these individuals and others like them experience a multitude of issues that are bringing them

into a cycle of hospital visits, both in-patient and out-patient, interaction with the police, courts, correctional facilities, probation and services which provide temporary housing. The cumulative financial impact is significant and does not serve the clients well.

Looking at the number of types of contacts and service usages only tells us part of the story. What those are showing us is the result of what brought them to that point, particularly in the case of police, courts, custody and hospital contacts, so we need to look at what preceded those contacts to understand what is going on.

In looking at those cases that have come to service resolution for the dually diagnosed in my service, the most common issue, be that the presenting issue or what has led to other problems, is appropriate housing. I say "appropriate" because most of the folks have had a number of failed housing placements. For those who are dually diagnosed, their needs in terms of housing can be very high. What they need is a place to call home that is equipped to deal with the challenges they can pose. These folks generally have very little insight into their mental health and developmental conditions. This often lends itself to making very poor choices about their lifestyles, leaving them vulnerable to various types of abuse if left to their own devices. This includes substance abuse, befriending and/or being used by other people who often get them into trouble with the law, financial abuse and medication non-compliance.

When we have somebody with a dual diagnosis who starts using substances, they become even more difficult to find a home for. The substances will complicate both their mental health and developmental issues. Depending on their drug of choice, over time their cognitive functions may become even more compromised, leading to increased inability to care for themselves, as well as lending itself to more psychotic episodes which will, again, result in increased visits to the emergency department and/or in-patient admissions. They are also at increased risk of legal involvement.

With someone with such a history, it's very difficult, if not impossible, to find any type of supportive housing that is willing to consider admitting the person. Placing them in an independent living situation is not viable, as often the person is not capable of managing on a day-to-day basis. Behavioural problems are often the reason for a failed placement. Trying to house someone in a setting where the staff does not have an understanding of the behaviours or how to manage them is a recipe for failure. Often when clients are stressed they can become verbally or physically aggressive. Depending on the individual, often the situation can be resolved through the use of de-escalation techniques, if you have properly trained staff.

There is a small group of people who do require a more secure setting due to their regular outbursts, which can be physically aggressive. These clients do need a hands-on approach, and may need to be placed in safe rooms for short periods of time. We do see clients that are in the community who actually need this type of housing; usually they are spending a significant amount

of time in our provincial jails. When not in custody, they're usually in housing for only a short period of time before offending again.

There is another group of clients who also remain in hospital. In Waterloo-Wellington, that means they're at Grand River Hospital, in specialized mental health at Freeport. These folks are designated as alternative level of care, meaning that their active treatment at the hospital is complete and they are as good as the medical staff expect them to be. They're ready to move out. However, even with the program that I mentioned before, that enables individuals to get out of the hospitals with extra supports, we usually don't have suitable housing to manage their behaviours, so they sit in the hospital at an approximate cost of \$1,000 a day.

Another area of concern is the lack of coordination between ministries. For my purposes, I'll again just focus on the housing issue. We have, of course, two streams. We have the developmental sector stream, which does have more housing but, as you've heard before, the wait-lists are long. On the mental health side, we have a patchwork of homes which are run by individual organizations, and we have two homes for special care in the region.

The Homes for Special Care Program is funded by the Ministry of Health and provides additional monies to the operators of the homes, which are privately owned. They provide the care to the residents. Those homes for special care are staffed 24/7, and they can work with individuals who are relatively stable. Those people need medication management, meals provided, laundry, cleaning—kind of day-to-day type things. They usually require supports to go to appointments, and they may need occasional verbal de-escalation due to behaviours. They're not the highest-needs clients, but they do require close monitoring.

The problem is that only those with a strictly mental-health diagnosis qualify for the program. Those who are dually diagnosed do not. We know that a segment of the dual-diagnosis population can be successfully housed in homes for special care, as we currently have a few people who are living there, in a few of the private beds available within those homes.

In order to put them in those beds, funds from the service resolution budget are used to provide the top-up over and above what the client was able to pay on their ODSP. The number of people who can be helped in this way is minuscule; the service resolution only has a very limited budget and has to cover a number of different types of service gaps in the region.

In terms of residences run by community organizations, there are only two in Waterloo-Wellington that have the ability to accept dual-diagnosis clients. Again, this has only been possible through either service resolution funding top-up or our Extraordinary Needs Program, and there are very few spaces in these residences. They're small. Again, they are only able to take people who are reasonably well-stabilized.

So it would be helpful if the Ministry of Health and the Ministry of Community and Social Services could

work together to come up with a shared funding plan to support dually diagnosed people, not only in homes for special care but other types of housing, including community providers that are willing and able to provide the physical buildings but require funds to adequately and appropriately staff the homes, particularly high-intensity rehabilitation or treatment homes.

Just very briefly: We have ongoing issues in getting access to services, both in-patient and outpatient—so, clinical services. We have a lack of beds for in-patient assessment, diagnosis and treatment. We have a lack of specially trained physicians and trained clinicians, and we have a need for intensive education for those in the mental health clinical fields as they relate to dual diagnosis. Some work has been done in this area, but it remains an area for ongoing need and training.

The Chair (Mrs. Laura Albanese): Thank you. So we'll—

Ms. Adrienne Crowder: Sorry, if I can—

The Chair (Mrs. Laura Albanese): Oh, you will continue? Sorry about that.

Ms. Adrienne Crowder: Angela's role is adult mental health in Waterloo-Wellington. My service resolution role is children's services in Dufferin and Wellington, and also developmental services through the whole lifespan in Wellington and Dufferin.

Just to give a little bit of context, only the cases that are at the tip of the iceberg come to service resolution, but, by virtue of the fact that they've risen to the tip of that iceberg, you get to see where the breakdown has happened en route. So service resolution cases have that kind of oversight.

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In the children's world, the typical case sitting in service resolution will have representatives from children's mental health, the developmental sector and education and then sometimes some specialty services. In the adult world, typically representation is developmental services and sometimes adult mental health, and often justice is involved.

What I want to do is just give a very quick breakdown of what the overall picture looks like and then go into some of the thematic challenges. Just to give you a sense of what a service resolution role and caseload looks like, last year, 2012-13, 72 cases came through Wellington and Dufferin; 42 were children's cases and 30 were adults; 61 were in Wellington; and 11 were in Dufferin, just in terms of slicing and dicing the numbers.

In the children's cases, 63% of the cases had an autism spectrum disorder diagnosis; 18% had a fetal alcohol syndrome diagnosis—I'm mentioning that because fetal alcohol doesn't have any dedicated services. There are no camps; there are no specific behavioural programs, and yet they're a bunch of children who have very high needs and who present major challenges to the community to respond to their care. Thirty-eight per cent had aggressive behaviours in the children's world; 36% had been hospitalized at least once before coming to service resolution; 23% had a modified school day; 9% were in section 23 classrooms; and 4% were not in school at all.

In the adult cases, 27% had no permanent housing; 45% required 24/7 care; 45% required modified support, meaning up to six hours per day; 33% had been hospitalized at least once prior to coming to service resolution; 13% were directly connected with the justice system; 45% had a dual diagnosis; and 40% had an ASD diagnosis—so just a sense of who comes through the service resolution process.

I want to speak to three key challenges. One of them you've heard repeatedly. Forgive me; I have to throw my hat in this ring too because it is such an important piece: housing. In Wellington county, the Developmental Services Ontario is aware of at least 60 clients who would take 24/7 care today if it was offered—that's a DSO process in terms of how they would qualify someone. We have, in Wellington county, at least 60 people. We have about three vacancies a year. Those vacancies become due because someone dies or someone leaves the county. There is a gargantuan gap between the need and the resources. Out of those 60 people waiting, we know that at least a third of them are between the ages of 18 and 30, a third of them have high behavioural and self-injurious behaviours, and a third of them live in Guelph. Those are some of the breakdowns of who needs that housing.

I have this in my written document, and I'm sure you've heard this from other people: The level of support that has gone into other service systems such as education has been disproportionate compared to what has happened in developmental services, where the needs are great and the funding has been low. I guess my question is, how does this make sense? Where can we begin to close a gap that is this size? How quickly can we put a solution in place? We have a vulnerable population who, by definition, cannot advocate for themselves. In a relatively wealthy province, it's very hard to work in a system where you can't help your clients.

Group homes are not a one-size-fits-all solution. There are many people, as Angela mentioned, with dual diagnoses who are not well suited to live with other people. Their needs are not ever going to be social in how they work. There really need to be some much more innovative models. The model we just heard about in Elgin is the kind of model that really responds to some of the ways that we can serve people.

Housing was the first thing. The second one is that how families with developmental services are funded and supported is really inadequate. Special Services at Home is a maximum of \$10,000 per family. ACSD is income-based, and if you have an income of over about \$50,000, you don't qualify. The amount of care that high-level children need in terms of respite over the summer holidays and Christmas and winter breaks is huge; families cannot afford, and there are not the resources, to house these people in respite.

Parents absorb the challenges of raising their children with developmental disabilities, and many burn out. Sitting at the service resolution table, I hear of single mothers developing cancer at a rate that is way above

random. I hear about couples divorcing, which results in precarious care and support for already vulnerable children. Parents report broken bones, severe bites and concussions from attempting to redirect aggressive children. In 38% of the kids who came through service resolution, aggression was a key component.

There is a huge family violence epidemic, I would say, in our province that is basically hidden. The level of physical harm that goes on in families is staggering, and it's apparently acceptable because the children are—it's non-volitional and the children can't help themselves, but the cost to our communities is massive: through health care, through the cost to families and the cost to those children.

Parents need skilful coaching and hands-on support. They do not need consultation; they need hands-on support to raise a child with developmental disabilities. They need to know they're not alone and that they can access flexible responses as they need them. Parents need good respite and they need enough of it.

I'm very passionate about this. I have had a long career in social services in Ontario. I had not worked in the developmental sector until about three or four years ago, and my eyes were opened. I didn't think I was particularly naive; I was very naive.

The third piece I want to speak on is the schools. Although schools are mandated to support children up to 21, how that gets operationalized varies from school board to school board, school to school, principal to principal and teacher to teacher. Some children are getting wonderful experiences. Someone with exactly the same behavioural or diagnostic profile living two streets over going to a different school may be having a terrible experience. In service resolution, I have had more than one eight-year-old who's not in school because the school cannot handle the aggression. That has this huge compounding effect. The child doesn't get their social needs met, the parent gets burned out, and the school doesn't have to step up and address the fact that they've got difficult children in their boundary whom they need to work with. It's very compounded.

I would really encourage there to be a way, if the province could possibly find a way, to hold schools more accountable for actually delivering on the services that they are mandated to deliver. That would really be a very helpful step.

Forgive me, I need to breathe.

I do appreciate the opportunity. Working in the service resolution role, there's an opportunity to help, but we can't help enough and we can't help in the ways that are needed.

The Chair (Mrs. Laura Albanese): Thank you. Did you need to add something in?

Ms. Angela Allt: We're just going to do a quick closing.

Housing is key. We don't believe anyone would suggest that we go back to the days of large institutions to house people. Indeed, we want to see people not just housed but have a place to call home. However, the

institution of the correctional facility all too often seems to be where a number of our clients end up spending significant amounts of time.

Appropriate housing for the dual-diagnosis clients could be best realized, as we said, by joint consultation between the Ministry of Health and MCSS and joint funding; provincial standards for clients with developmental disabilities in terms of health care services for addictions; developing a process that tracks clients across the service system so that the total cost of hospital time, jail time, court time, ER time etc. is available—and it will be cheaper to house and support clients appropriately in the community rather than having costs hidden in multiple service systems; and resourcing schools so that they can serve the clients with challenging developmental disabilities, resulting in no client with a developmental disability being sent home based on their behaviours.

The Chair (Mrs. Laura Albanese): That doesn't leave any time for questions, but at the same time, I want to first of all thank you on behalf of the committee for the work that you do and for the wonderful presentation you gave us illustrating some solutions. Thank you for all that you do.

Ms. Sylvia Jones: Chair, while the next presenter is coming up, can I ask a question of the researcher?

The Chair (Mrs. Laura Albanese): Absolutely.

Ms. Sylvia Jones: I want to confirm I heard that right. Homes for special care are not available to dual-diagnosis clients: Can you delve into that for us? Thank you.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: I also noticed that there were quite a few questions that the previous witness shared with the committee—and if the researcher could also get some answers for the committee. On the last page of the handout that was shared with us, how do great models of support—can we identify some of them? About the school boards: This is not the first time this committee has heard about the inconsistencies of school boards in the delivery of services. I am particularly interested to know—on page 2 of the report, the witness talked about increased funding to the Ministry of Education, 172% over 10 years, despite declining enrolment, yet another ministry has greater needs and less funding. Can we get some answers?

Where's the accountability when we give extra funding? That's why I'm trying to get some answers to those questions that have been identified by the previous witness.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Wong. We'll welcome the next presenter at this point—

Interjection.

1010

The Chair (Mrs. Laura Albanese): Sorry? You had more questions?

Interjection.

The Chair (Mrs. Laura Albanese): We'll move on to the next presenter?

Ms. Erica Simmons: Yes.

COMMUNITY LIVING
OWEN SOUND AND DISTRICT
COMMUNITY LIVING
WALKERTON AND DISTRICT

The Chair (Mrs. Laura Albanese): Mr. Hill, executive director of Community Living Owen Sound and District and Community Living Walkerton and District, correct?

Mr. Rick Hill: That's correct. Thank you.

The Chair (Mrs. Laura Albanese): Welcome. You may begin any time.

Mr. Rick Hill: Thank you. I have my notes written down, so I'll read them. That way I know I'll stay within the time limit; excuse me for that.

My name is Rick Hill, and I'm executive director of both Community Living Owen Sound and Community Living Walkerton. I mention that it is my 30th year of work in the Community Living business. One of the unique aspects of work in a Community Living organization is that the work we do does span entire life cycles from birth to death, as an intellectual disability is a condition present throughout a person's life.

What we have learned in our work is that the earlier the intervention, the better things are in the long run. People who don't work in this field often believe that it's special work, that it's not like what is experienced by the so-called norm. It's special work for sure, but not for that reason.

Let me give you an example of how it's much like everyday life for people. One of the employees at Community Living Walkerton just returned to work after being on maternity leave for a year, with her first daughter. Co-workers were asking Mary how her daughter was managing the change with mom at work. She said she was doing well, as she had been preparing her for this day over the past few months, leaving her with different sitters in her home and in other people's homes. This early intervention proved helpful for both babe and mom. A similar story could be told for any stage of life, whether it's going to school, whether it's graduating or whether it's getting your first job etc. The earlier that you begin on that path, the better.

This basic understanding of human development is ingrained in the thinking of developmental services professionals but is less obvious in other sectors. Can you think of another line of work or sector that requires this lifelong perspective to be applied to all of their work?

The reason I'm focusing on this aspect is that in preparing this presentation, I have noted a shift over the past 10 or 15 years whereby responsibility and authority for publicly funded developmental supports and services has been divested, downloaded or dispersed, depending on your definition, amongst multiple ministries, and that the primary authority of MCSS, Ministry of Community and Social Services, has become focused exclusively on adults, leaving no one with an overall authority or eye on the big picture. Decades ago, as closure of provincial institutions for children and for adults with development-

al disabilities was the vision, a system of community supports was put in place through partnerships with community-based organizations. The vision included programs for infants, preschoolers, youth, adults and seniors, all under the authority of MCSS.

This was in the 1980s, when I first started in the field. I recall many meetings talking about making sure that a full continuum of services was in place. Special initiatives were undertaken in areas such as dual diagnoses, supported employment, Special Services at Home, family support. Over time, the gaps seemed to be covered, and the task then began to get the right mix of services.

Then of course, budgetary pressures began to impact, and recessions of the late 1990s began a trend of dismantling or dispersal of programs from the authority of MCSS. I'm proposing that the select committee consider the impact this divestment has had, which creates unnecessary transition points between funding silos and removes the benefit of overall authority for the full funding envelope. Might this divestment be one of the primary reasons why a select committee is needed today? I believe the approach of having multiple ministries each responsible for small portions of publicly funded services forgets the fundamental principle of lifelong continuum and early intervention.

I have a couple of examples of how this plays out. In the Ministry of Children and Youth Services' presentation that the select committee heard early on, it was stated that there were only two programs provided by MCYS that specifically targeted children with a developmental disability. Those were identified as programs related to autism and the Infant Development Program. I want to speak about infant development programs.

There are 49 programs in the province and two sponsored by the organizations that I lead. As the name suggests, the program is for infants, and the funding criteria specify that the infants served must have an identified delay or be at risk of delay. Indicators of being at risk would be such things as low birth weight, premature birth or multiple births—twins or triplets, for example.

Infant development programs typically use a home visiting model. The infant development professional works with both the parent/caregiver and the infants, using play and often physical therapies. Infant development staff are trained to administer many assessment tools to help pinpoint areas of delay and serve a case coordination function, with referrals to other services when indicated. Most importantly, parents and caregivers are engaged in their child's development and learning, one of the few opportunities for parent engagement as we now embark on full-day learning in our schools by the age of four.

In Bruce and Grey counties, approximately 7% of all babies born are referred to the Infant Development Program. Annually, we handle about 160 new referrals each year, and we work with infants up through the age of five, although most are not seen beyond the age of four. Typically, the six full-time-equivalent workers in

Bruce and Grey counties are actively visiting 250 infants. That's a ratio of one worker for every 40 infants, more than double from when the program was first initiated; at the time, it had a ratio of 1 to 15.

The primary issue facing infant development programs is that the programs' funding level has not been sustained. When it was a part of the developmental services envelope under MCSS, it received the same attention as its adult counterparts. However, since the program has shifted to MCYS as a stand-alone program up against child welfare, children's mental health and even autism funding, the funding has deteriorated year after year, now going 12 years without any base increase.

Significant lobbying by program sponsors such as myself has only resulted in a series of reviews or studies, none of which produced any action. It has been stated by researchers that the return on investment of early intervention services is \$3 to \$9 per every dollar invested. Presently, it costs about \$1,800 per year per child for infant development services.

Provincially, there are 3,200 infants referred and waiting for this service to begin. As any parent knows, in what seems like a blink of the eye, your newborn child, your baby, is graduating. There's no time to waste in waiting.

Why has this program not been sustained? In my opinion, MCYS has been a poor match for it, a small, unnoticed program up against the MCYS backdrop of child welfare and children's mental health. The ID program belongs with the broader developmental services program funding under one ministry. I urge the committee to recommend restoring a sustainable level of public funding to this program and shift it from MCYS to the developmental services portfolio, wherever that is.

I also want to speak to another aspect of Early Years programs that also highlighted for me the fact that dissemination of the developmental services portfolio is a problem. Neither MCYS nor the Ministry of Education mentioned it in their presentation, but it's an important program in the developmental services life cycle, and that is special needs resourcing.

Special needs resources are funded as part of the child care envelope, once a part of the Ministry of Community and Social Services, then moved to MCYS and now moved on to the Ministry of Education. The Ministry of Education has bundled the child care funding with federal grants into an Early Years division, and it flows out to tier 2 municipalities. In my region, that would be counties.

As the name suggests, special needs resources provide preschool resource teachers to provide developmental programming for children with identified delays in two or more areas of their development. Unlike the Infant Development Program, where a risk of delay was a referral, in special needs resourcing, it would be an identified delay in two areas.

1020

In most areas of rural Ontario, where distance and transportation are a real concern, preschool resource

teachers travel and alternate their visits between the child's home and licensed child care centres. The goal is to help prepare parents engage with their child's developmental needs so that the child makes a smooth transition to school or to the child care centre.

Since taking on the special needs resourcing program, the Ministry of Education has revised the guidelines for the program. These revised guidelines would eliminate or greatly reduce the home visiting component of this service. This would effectively remove the parent engagement component of the present special needs resourcing model. In rural Ontario, there are many reasons why parents may choose or may not be able to have their child with special needs attend child care. Removing their children from the special needs resourcing program will only increase the caseloads on the already oversubscribed Infant Development Program, which is the most commonly referred-to program for infant development.

Once again, when funding specifically for children with developmental needs becomes managed by ministries who do not see or appreciate the lifelong journey, poor decisions are made. It's easy to see how, when the Ministry of Education, which is primarily focused on and accustomed to an institutional model of service, encounters a program or service like this, silo thinking takes over, and it rationalizes focusing child care funding on only child care centres.

The final example that I wish to cover in the presentation deals with another program noted in the MCYS presentation, and that is funding that is attached to children with complex special needs. The presentation noted that funding for this program has increased from \$22 million in 2002 to \$105 million today, and the number of children served is now over 800, a good number of them living in children's residential services.

While it was suggested that the program serves a target population broader than developmental services, I would ask the committee to confirm this, as I would estimate, based on the numbers I see, that a very high percentage of children and youth served end up making a transition to adult developmental services. I believe that it would be as high as 90% of the children.

Once again, my point is that by establishing the program under MCYS, a new transition point is created. Children with complex special needs become adults with complex special needs, and this dual authority creates inefficiencies, gaps and, goodness knows, undue stress for families and individuals.

I know of one instance where a young adult who was involved in a complex special needs program now has his adult funding spread over two different service agreements, one with MCSS and one with MCYS, and that budget is also spread over three separate line budgets, all within the same agency. So when each of his team members sees him, works with him, we as a service provider need to allocate costs across three different budgets. It's the same worker, same person, no difference in the service area or the support being provided, but the cost splits three ways, and not in three equal amounts, either.

Also, each budget has its own service targets and reporting requirements.

This young person's family must worry: What happens to this young adult, with his complex special needs, who is going to need lifelong support, when the Auditor General or some other controller asks, "Why is MCYS funding services for a 30-year-old?"

I wrap up by asking this select committee to restore the funding for the Infant Development Program and sustain it, and gather all the multiple funding envelopes specific to developmental services under the authority of one body.

Over the past few years of so-called transformation of developmental services, one would think people inherited an intellectual disability at age 18. This has created unnecessary and costly transitions, and also meant that services for infants, children and youth with intellectual disabilities have been cut adrift.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. I believe it is—no, it's your turn. So Ms. Elliott.

Mrs. Christine Elliott: Well, thank you very much, Mr. Hill, for your presentation. What you said makes a lot of sense to us. The Infant Development Program is something that I wasn't aware of, so thank you for bringing it to our attention, that the funding had been decreased for that.

One of the things that we also have noticed is that there is no one with a central responsibility for developmental services. It's very fragmented. Do you think that MCYS really needs to be involved in this aspect of it at all, or could everything be consolidated into the one ministry, into MCSS?

Mr. Rick Hill: I think there are different models, and I think it's worthwhile to take a moment and look at it. This hasn't been a big point of discussion with my colleagues across the province in terms of how it would look if different. But certainly in British Columbia, for example, the government has assigned all of the funding envelope not to a ministry, but sort of to a crown corporation notion. You're well aware of the different options available.

I just think that the more you spread the funding out, the more transition points you get and the more need, then, for inter-ministerial work, and the stars never align, in my mind.

Mrs. Christine Elliott: I'm not sure if I have time for one more question, but I'll try to get one in. Could you just speak to some of the particular challenges that you face in a largely rural area?

Mr. Rick Hill: Specific to children, just to mention on that, one of the advantages is that you don't have a lot of overlap, so there aren't a lot of different programs. A Community Living organization in rural Ontario serves a lot of need. But for children and youth, the issue around the special needs resourcing in child care is with the changes in the full-day learning. Children are, of course, now eligible for school at an earlier age, and most

children with special needs are taking advantage of that. The aspect of rural child care is a real issue. Layer that, then, when you have a child with special needs, how they manage in that child care centre, for example—it becomes a real problem. I don't have the solution today, but I'm just pointing that out as an example of how one ministry that has a different focus applies a different lens to the solutions there.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): And time is now up, so we'll go to Miss Taylor.

Miss Monique Taylor: Thank you, Chair. Good morning. Thank you so much for your presentation today. I also had not heard of the Infant Development Program, so I'm glad that you brought that to the table today.

You mentioned that there were 160 referrals every year. Do you have a number—and I may have missed it; I apologize if I did—of how many are actually being served? Is it just the 160 and then—what are the numbers?

Mr. Rick Hill: All of the 160 would be referred and seen, so there would be, actually, 160 new referrals each year that do get service.

Miss Monique Taylor: Right, and they're referred, I believe, at birth, or—

Mr. Rick Hill: We have referrals from, for example, pediatricians as late as three years old or older, so they don't all come at birth. As milestones are missed or as delays or concerns are raised, then a referral gets made. It's not all babies, infants, newborns who are referred. They're of different ages.

Miss Monique Taylor: You were saying that the funding hasn't increased in 12 years. How much of a deficit are you feeling? What's your situation?

Mr. Rick Hill: In the example of Community Living Owen Sound, we have approximately three full-time infant development workers, and we reduced that by half a position in the last five years. The impact is that you rob Peter to pay Paul. The manager is no longer half-time; she's quarter-time. As sponsor of the program, you inherit other costs when one program hasn't been keeping up. In Grey-Bruce, we've reduced a full-time FTE, one FTE, over the last five or six years by not replacing workers.

1030

Miss Monique Taylor: So is there a wait-list—

The Chair (Mrs. Laura Albanese): Thank you—sorry.

Please answer.

Mr. Rick Hill: Yes, there is a wait-list. Provincially, I mentioned that there was a wait-list of 3,200 infants. It varies depending on, of course, the birth rates and the different geographies etc.

The Chair (Mrs. Laura Albanese): Thank you. Yes, Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much for your presentation. You talked about how to coordinate the services across ministries. That's part of the intent of what

we're doing here through the select committee: to look at that coordination through a person's entire life and how we provide the appropriate levels of support, so your input and the insights that you have from the work that you do across such a large geographic area is extremely valuable.

You talked about the models that could potentially be looked at, and you mentioned British Columbia. I'm wondering if you could expand on some of the things you see that are advantageous in that consolidated view.

Mr. Rick Hill: I think the select committee would have a lot less of a problem getting answers if it was consolidated funding. I think this is a special population of people that we're dealing with. They have very unique needs. You've heard some of the stories today; they're unlike any other sector that we're responsible for. They're vulnerable people, people with all different needs. I think that the more we can do to keep an eye on the big picture there, the better. If you take a pie and you divide it up, the next thing you know, everybody goes home hungry. It's too hard. My suggestion is to take a look at that as an option and consult with the partners.

There's a need for our medical community to respond to people with developmental needs. I'm not saying "special doctors for this population," but where funding is primarily focused on children or adults with developmental disabilities, then I suggest that it be put in an envelope and looked after and managed that way.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before our committee this morning.

Mr. Rick Hill: You're welcome.

MS. JOANNE SMITHERS

The Chair (Mrs. Laura Albanese): I will now call on Joanne Smithers. Please come forward. When you are ready, you can start your presentation by first stating your name for the purposes of Hansard.

Ms. Joanne Smithers: Thank you. Sorry; I'm suddenly nervous here. My name is Joanne Smithers, and I have been front-line staff with Community Living Guelph Wellington since 1999, working in a variety of programs including behavioural and medical homes. I'm currently in a home in Mount Forest, Ontario.

In my role as a support worker, I have the responsibility of advocating for those in my care, of giving voice to those who can't always speak for themselves. That's what I'll try to do here today.

I also have a dual role, however. I am the president of my CUPE local, representing 430 staff—the majority of whom, you should be aware, are mostly women. I'm also here to represent them today.

I'd like to start out today by introducing you to the people who I support. They are unable to be here today, so I will be passing around some photos and telling you a bit about them. Just for clarity, my executive director has given me permission to share these with you today.

I'll start with Bev. Bev is a 68-year-old gentleman who formerly resided at Midwestern Regional Centre.

Bev is non-verbal, but he will grunt, groan and yell at times to show you what he wants. Bev has limited mobility due to advanced arthritis, and he now requires a wheelchair or staff to walk him. Bev has pica tendencies, which means that at times he will ingest latex gloves, strings, carpet and drywall. Bev loves horses, he loves watching movies and he loves van rides. Bev requires staff to toilet and bathe him, and Bev requires 24-hour care and supervision.

This is Shaun. Shaun is a 34-year-old gentleman who lived at home with his mother prior to coming to Community Living. Shaun's mother, unfortunately, has now passed away. Shaun has Down syndrome, he's hearing impaired and he is completely non-verbal. Like Bev, Shaun also has pica tendencies; Shaun will ingest latex gloves, balloons, plastic bags, strings, feces and yard debris such as grass and dirt. Shaun loves repetitive motion, and he has a swing set that he uses in the winter months. Shaun likes to float around in a swimming pool, and Shaun also requires 24-hour care and support.

This is Marleen. Marleen is a 58-year-old woman who, prior to community living, lived in a nursing home. Marleen has an unknown condition that is now causing severe deterioration of many of her skills and abilities. Marleen is unsteady on her feet, and she is no longer even semi-independent. Marleen used to be able to use some limited vocabulary, but she has now lost that ability. Marleen loves to colour. She loves to go out, especially for coffee or when I take her shopping. Marleen enjoys simple one-on-one time with staff doing things like just colouring or painting her nails. Marleen has seizures, and she requires staff to toilet, bathe and, now, feed her. She requires 24-hour care and support.

This is Penny. Penny is a 62-year-old woman who has been institutionalized since birth. She was expected to have a very short life, and she has proven everyone wrong. Penny is blind; she has epilepsy and chronic aspiration. Penny doesn't like to be around people much. She prefers to spend time alone in her room, and that is where she is the most calm. When agitated, Penny will hit herself on the head and she will poke at her eyes with her fingers. Penny caused her own blindness many years ago with this self-injurious behaviour. Penny is in a wheelchair and she wears a brief. She requires staff to toilet, bathe and feed her, and she also requires 24-hour care and support.

Finally, I want you to meet Paul. Paul is a 55-year-old gentleman who formerly lived at Midwestern. Paul is probably the most independent of the people I support. Paul cannot walk, but he crawls and pulls himself around with his arms. Paul is non-verbal, but he can understand most things that staff tell him. Paul has a wicked sense of humour, and he often laughs at staff and his housemates. Paul likes to go out one-on-one. Paul doesn't like to be crowded, and he will hit if he feels people are too close. Paul loves music. Paul also requires 24-hour care and support.

These are just five of the 138 residential clients that Community Living Guelph Wellington supports. We also

provide support to 176 people in vocational programs, 155 in life skills and 98 in supported independent living. I believe we can provide quality public, not-for-profit support through our agency, with an emphasis on individualized planning, not individualized funding, but we need your help.

The people we support are aging. Their needs are increasing and are becoming more complex. We need more resources, not less. A year ago, Community Living Guelph Wellington was forced to cut 90 hours per week, and most of these were direct-support hours. These cuts have had a direct impact on the people we support. The cuts have impacted the ability of staff to get the people we support out into the community as well as increasing the amount of time staff are required to work alone. Just picture having to provide all the supports to the people I have just told you about today and then having to do it alone.

What it means is that we're less able to take Marleen out shopping or for coffee. I'm less able to just sit and paint her nails for her. I have less time to take Bev out for a drive to go look at horses or to take Paul out one-on-one for a van ride. Shaun has less ability now to go swimming. These are the things that make their lives special, and without these, all we have done by closing the institutions is change the room they're sitting in.

We all know there are wait-lists. Different people seem to have different numbers, and I'm not sure this committee has even been provided with complete numbers on this. We know that in crisis people are being placed into long-term care, and we have heard that they're also taking up beds in the youth system, unable to move on to the adult system, which is causing a wait-list for those services.

Why did we close the institutions just to reinstitutionalize the people by putting them into long-term-care homes? I have to wonder if in 10 years the government is going to have to issue an apology to these people. Once someone is placed in long-term care, do they come off the list of those waiting for beds in the DS sector? I suspect they do. Would this not skew the numbers of those on the waiting list to make it seem smaller?

1040

Currently it seems we are providing a reactionary support to those coming into service. I believe these must be more expensive and they are tremendously stressful for the families, but, more important, for those we support. When we have parents in their sixties, seventies and now even their eighties being forced to care for their children, we all know that a crisis is waiting to happen when they die. Parents have told me they are terrified of what will happen then. They know chances are there's no way they are going to get a placement before that happens.

Once the parent passes away, we are now in crisis mode. We now need to find emergency services for the person who is struggling with the loss of a parent and possibly the only caregiver they have ever known. They are losing their home and familiar surroundings,

suddenly having to live in a strange environment with strangers and not able to understand what has happened. There is no way to do a gradual transition. Many of the people we support have huge difficulties with any changes in routine. They deserve better than this.

Many agencies are dealing with aging infrastructures, homes that were not designed for the complex needs of the people that we now support, putting a large physical burden on the staff that is providing those supports. As we have heard, we have homes that do not meet the new fire codes. Community Living Guelph Wellington has not as yet had the order to put in a sprinkler system, but from what I have been hearing, it's coming. This scares me, as that money will have to come from somewhere.

Our vans are aging and they need to be replaced. Costs for hydro, food, and general care needs have all increased. The people we support are now having to pay for more and more things agencies used to provide. This sector needs more funding.

The agencies are falling behind on pay equity, as you have heard. This is causing many employers to worry about unpaid liabilities. Yet the women in our workplace deserve equal pay.

As you have heard from many employers, retention of qualified staff is a large concern. Community Living Guelph Wellington staff agreed to take three years of wage freezes. Add to that that staff have not received pay equity since 2010, and then the cuts to hours mean many staff are now making less than they did in 2010. The staff at Community Living Guelph Wellington have identified this as a serious issue that must be dealt with in upcoming negotiations. We simply cannot fall further behind.

Many but not all of the parents I have spoken with are asking for more individualized funding because they know they have no hope of getting a suitable residential placement. Many of the others that do want the individualized funding for now also acknowledge that at some point as they age they will need agency residential supports and are worried about the ability to access these in the future. Our sector needs more funding. Parents should not have to live in crisis.

Finally, I cannot stand up here and ignore the fact that over 100 collective agreements in this sector are expiring on March 31. Failed promises, lack of funding and poverty among staff are at a boiling point. Staff feel they have been ignored and overlooked for years. We are not babysitters; we are professionals and would like to be recognized as such.

In a recent survey that my local did, staff indicated that they can no longer continue without increases to wages and benefits. They identified equally, however, that they were worried about job security and workload among staff, as we're working alone more often. For years we have been told we have to do more with less, both on the job and in our personal lives. Staff have indicated they can no longer continue in this way. Something has to be done. The people we support deserve better, and so do the staff that provide those supports. Thank you.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much, Ms. Smithers. We now have approximately three minutes each for each of the parties to ask questions. Ms. DiNovo, would you like to start?

Ms. Cheri DiNovo: Sure. First of all, thank you very much, Joanne, and thank you for being privy to—being here, listening to all the other presentations.

A couple of questions, actually, for research. I think we've asked these before, and I'm not sure we've had answers yet.

Wait-lists: We asked the ministries this and they didn't seem to be forthcoming. We need to know how many people are on wait-lists for all the services and we still don't have that.

Long-term care: We've asked a couple of times now how many people with developmental disabilities are in long-term care. Again, we need those numbers. Again, ministry—I know we have ministry folk here—we really need to know that. You raise the issue of, "Are they coming off?" If they're in long-term care, if they're coming off wait-lists in the DSO, we need to know that as well—so those three things.

For you, Joanne, just in terms of others, is there a jurisdiction that does things better? If you look to a jurisdiction—we're sort of mired in all of what's wrong with our system, and there's clearly lots wrong with our system. Is there some place that's doing it better?

Ms. Joanne Smithers: I'm not sure. I know there are researchers out there who have looked at different models and different things. I believe it's Saskatchewan that now mandates services, so it's not a choice anymore. There are no wait-lists because you have to provide services, which I think is something that Ontario really needs to look at. I know from just general talk that I have heard that the UK and Australia seem to do it better than we do. Australia also no longer has wait-lists and that.

Ms. Cheri DiNovo: Thank you.

Miss Monique Taylor: Thank you for being here with us and for spending all of your time with us as we've been going through this process. You've been at every single hearing, and we appreciate that. I also really want to thank you for bringing the voices of the people who you serve to our table today and describing what their life looks like and what their needs are.

I'm quite concerned with the lack of funding and the increase in base funding that your sector has received. What's going to happen with those folks as we continue to go into years of an aging population?

So I just want to thank you, and if you have anything else to add during my time, you're free to do so.

Ms. Joanne Smithers: No.

The Vice-Chair (Mrs. Christine Elliott): We'll now move to Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I note that you have identified a number of concerns and issues to this committee, so can you share with us, in your final comments, what are some of the priorities? If you wave a magic wand, what would be one

priority that, in your sector, you think would be the first thing we should consider?

Ms. Joanne Smithers: Well, I think probably the biggest priority has to deal with the wait-lists. I think there are too many people who have absolutely no access to services, and then when they do finally get services, it's in crisis mode, which makes things much, much more difficult for the staff who are having to look after the people, as well as being really difficult for them. I hesitate, though, to put that above trying to retain qualified staff because I believe that that also benefits the people we support. I don't think you can do one without the other, and the fact is that retention in this sector is becoming a very big problem.

I had a co-worker who works full time, and she had to go out last year and get a second job. She took a job waitressing at a truck stop, and she was shocked because she said she made more money there.

Ms. Soo Wong: Do we have more time, Madam Chair?

The Vice-Chair (Mrs. Christine Elliott): Yes.

Ms. Soo Wong: Okay. We have heard consistently now about the concern with DSO, and we also heard that we need to be more centralized, or have one ministry lead the delivery of programs and services. From your experience and your professional work in this area, which ministry would you consider? Or should we be looking at a crown corporation like they do in BC? If you could share that view with us.

Ms. Joanne Smithers: Off the top of my head, I want to say the Ministry of Health because they have more money. But we all know that with dual diagnosis—I don't know what the answer to dual diagnosis is because they fall under both. So I don't know what the answer to that part is.

What was the second part?

Ms. Soo Wong: In terms of centralized delivery—

Ms. Joanne Smithers: The DSO—I don't deal directly with the DSO, so I really can't answer that. But from what I have heard from parents and what I've heard at this committee, the DSO seems to me like it's a lot of money going on administration costs that could be handled by the agencies themselves and perhaps go to front-line services.

Ms. Soo Wong: Thank you very much.

The Vice-Chair (Mrs. Christine Elliott): Now we'll move on to Ms. Jones.

1050

Ms. Sylvia Jones: Thank you very much, Joanne. I gather from your initial comments that you do not support individualized funding at all.

Ms. Joanne Smithers: No, it's not that I don't support individualized funding, because some of the parents really, really do like it. I'm just more concerned with us focusing more on individualized funding when even those parents have said that at some point they are going to need agency funding.

Ms. Sylvia Jones: Yes, I think that's partly what we as a select committee are trying to do, from that diagnosis

right to the end of life, because, to your point, we have supported independent living, we have respite care, we have work programs, so some way, over the period of a client's lifespan, they're probably going to tap in to multiple programs. I think that's why a lot of parents like the individualized funding: because it gives them some options and input into, "This is where my son or daughter is at this particular moment in time." I think we have to do a better job of making sure that individualized funding is available to the families and the individuals who need it, but I would hate to see it disappear.

Ms. Joanne Smithers: I do have one concern with individualized funding—and I don't know exactly how it works. It's more on the accountability piece of it, because parents get a pot of money and then they have to decide how to use it. I have a number of staff and I've talked to a number of staff around the province who work for parents and are paid cash under the table because the parent says that they can pay them, then, \$12 or \$13 an hour cash—they don't have to pay taxes on it—so they can get quality staff that maybe at an agency are making \$20. I don't know exactly how that accountability works, but I know I've heard this from more than one area: that a number of people do it under the table so that they can get more services for the money.

Ms. Sylvia Jones: One point of clarification: They actually have to present a program and a vision and an idea of how they're going to do it. There's no family that's just getting a cheque with, "Go ahead and spend it"; you have to actually put together a proposal that's quite detailed. I guess to some degree, that's why it's so frustrating for parents when they've gone through all of that background and work to then be told, "There is none. We don't know what the waiting list is, we don't know when you're going to get it, but good luck."

Ms. Joanne Smithers: Yes.

Ms. Sylvia Jones: Thanks for the presentation.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much, Ms. Smithers, for your presentation today and for your ongoing support of the committee.

MS. LYNN HAINER

The Chair (Mrs. Laura Albanese): Now we ask Lynn Hainer to come forward.

Ms. Lynn Hainer: Thank you very much. You have my presentation coming around to you here.

I come with a few different hats today. A few of you I've met before, so it's nice to see you again. First, the reason I'm here is mostly because of my son, Mitchell, who is now eight, but I also sit as a councillor in the town of St. Marys. I'm an accessibility committee member. I sit on the local advisory committee for the St. Marys Memorial Hospital and within the HPHA. As well, I'm the former chair of Parents in Perth, which is a family organization in Perth county. I also sat as a SEAC member for Avon Maitland District School Board. I hope to bring a little bit of a different context to some of the things you've heard today.

Slide 2: I've named it "Mitchell Inc." because my son's name is Mitchell and it is a business. It has been a full-time job for me for six years. We were living in Toronto and we decided we couldn't keep up with the pace anymore. We decided to relocate back to St. Marys, which is my hometown. That full-time job, we've now taken to a close. I now work full-time. I now know that I have 10 years or so to actually contribute financially to my family. We're going to take that time to make sure we are setting up a future for him and for us.

On the front page, you'll notice our family picture, which is my husband, Rick, and my daughter, Johanna, who is two years older than Mitchell.

Mitchell has a rare condition called Pitt Hopkins syndrome. I've given you the URL there. We would love for you to come and take a look at the website to learn a little bit more about it. Just to give you a context, when we first went through genetics testing, there was no blood test available for his disorder. There are only 200 children around the world who have it, and he was two before there was that blood test. He was successfully diagnosed at the age of four.

Through some parent-funded international research, we now describe Pitt Hopkins as having a severe intellectual disability, hyperactivity, non-verbal and on the autism spectrum. The reason I put that last piece in is because of the number of times doors were closed when Mitchell was a child for receiving autism services because he didn't fit the required diagnosis for autism. I understand that with the new autism criteria today, he still would not qualify for those services even though researchers say he's on the spectrum.

I wanted to comment on the previous presentation a little bit about early intervention. We had really great success in Toronto, actually, with Surrey Place and others that provided care for Mitchell. The CCAC was on board: We received OT in the home and it was very successful for him. He didn't sit until he was two and a half, so he had real physical issues, and he didn't walk until he was almost four. So again, the path that he has taken is just tremendous.

Moving on to the next slide: I put this first because our priority as parents, first, is to keep Mitchell safe. What I found as he was growing was that every six months, there was something new that we were dealing with related to his curiosity and his skill sets completely changing. What we've found now is that we're really worried about his lack of understanding of danger, from crossing the street to wandering off, stranger danger and dangers in the home—so hot water in taps, stoves, stairs, choking and general falling because of his gait. What we found was there were no funding programs to help us to make sure Mitchell was safe in our home. They would rather have him go somewhere else, should there be somewhere else to go, than help us put in those little things that would make it safe for him. Two easy things, which I think are currently in the program, would be to extend the eligibility for the Healthy Homes Renovation Tax Credit to anyone who is eligible for the T2201 Disability Tax

Credit. Right now, it's seniors only, but our kids fit into the same dangers that you're finding with elder care.

We've been very fortunate to receive March of Dimes funding for our home. We have an accessible washroom for Mitchell now—they widened a doorway for us so he wouldn't trip as often—and we have a ramp to the front of our home. Some of the things I asked for during that grant process were things like helping to reorganize my kitchen in a way that I could put up gates so he could be safe as an adult. My husband is 6 foot 6, so my son is going to be very tall. He can now step over the child gates we have in place. We don't have the next solution to this problem, and a March of Dimes program would be perfect for trying to deliver some of those solutions for families.

The next slide I've labelled Mitchell and Ian. I want to thank Ian's family for allowing me to talk about their relationship. Ian is a triplet, and another elder sibling. I was presenting for a Pitt Hopkins mothers' retreat in North Carolina a few months ago, and I wanted to get perspective about Mitchell from others besides myself. The reason I have the computer up here is I wanted to see if I could play the video so you can hear how Ian is describing their relationship. I will be around at lunch if you want to actually see the video.

Video presentation.

Ms. Lynn Hainer: I will leave that for later, then. Basically, what Ian is saying is that Mitchell cares about all of his class; he cares that everyone's included. He talks about the fact that Mitchell goes to visits him in the hockey game. Even though Mitchell can't play, he comes out and supports his friends. He really appreciates his friendships. If you have a chance, I'd love to show you during the break the video we had done for our Pitt Hopkins day.

1100

This is just a scenario that I'm looking at. As I sit here and I read your transcripts and hear the people speak, I almost think this is like A Christmas Carol. We've had our apology in the House for the past. We're now hearing the crisis of today. I want you to think of Mitchell and his peers as our gift for the future: things that we can be doing to reform the system today, to know that these younger children will have the experience of living a fully included life where they are safe and they have the supports they need. As I'm sitting here, I find that to be kind of a relevant story as we're moving through the different scenarios related to developmental services.

Mitchell, who is now in grade 3, attends and has always attended school with his peers, with accommodations and supports, but what will happen to their friendship as they age? How do we, as parents and as a community, encourage and support their friendship?

Mitchell's Special Services At Home funding is currently underfunded. We receive \$2,000 a year, which was actually transferred from the Toronto monies to us out in Perth county because there were no monies available when we did our move, so we thank goodness for that. But still, it's underfunded from what we qualify for by about another \$3,000, from the last time I've seen

the numbers. With the current processes, he will be wait-listed for Passport at 18.

How will Mitchell fulfill his participation commitment within their friendship? I really believe that community participation and inclusion is the obligation of the person being supported as well, and that they have commitments, similar to you in your adult friendships. You have a commitment to return phone calls, to be engaged and to be interested. If Mitchell doesn't have the supports available, he won't be able to hold up his end of the friendship and, really, how could his friends be expected to always do the work to make sure he's included? It has to be that two-way street and that's what the funding will do for him.

My vision of participation, as Mitchell becomes a teen, is that Mitchell and Ian will choose to go to the movies and also with their other friends, and that Mitchell will be able to coordinate his own support worker so that he can go. When Mitchell is 16, he and his friends aren't going to want his mom taking them to the movies, right? They're going to want some independence, and that's what he can do with his own support worker. That's my vision for where I see we could add value if we are changing the system.

The next slide: Mitchell's future. We look to support Mitchell to be able to share his gifts in a way that enables him to fully participate in his community. We're still learning about Mitchell's gifts, but we're watching, and are very open, to see what he offers to his friends and to his community, and we listen to that. But we also recognize the challenges with his disorder and his hyperactivity.

With that, recognizing his hyperactivity, we look to leverage his gifts with engaging others—so, a very social guy—but he also has to be very physical and active, so we envision a place where he could work, volunteer or even own his own business related to a sports industry. Imagine an indoor soccer camp, something that could include kids to adults. We have big visions for what Mitchell could accomplish, but he's going to need support, and he's going to need his family to be engaged in that process as well.

We're doing the things that we need to do. Mitchell has his RDSP. We are focused on our Henson trusts. We're doing all the things that we can, as parents, to ensure that he has the tools, that we can make this happen.

But we also want Mitchell to be able to communicate and make choices on where and how and who he's going to live with. I think that's very important. We, as adults, each get to choose those things in our lives, and I think all of our children can do the same.

Our plan is that Mitchell will end up having the family home and that Mom and Dad will move out, and that he will have roommates and that they will be supported in that home. Again, that's the vision. There are lots of rules and regulations. If I decide that Mitchell needs two roommates versus one—you know, going from a personal home to a group home—but those are, again, things that we have time to figure out and hopefully get the support through specialized, individualized funding and other supports for housing programs.

I've moved on to my next slide. I sit with and listen to the health care side a lot. I liked the phrase "right care at the right time in the right place." I think this is equally important to this committee, because I think that if you look at the context throughout what we're talking about, it fits very well into what the Ministry of Health is talking about, related to their services. Again, I keep that as kind of—if you're looking for guiding principles, that's one that I'd look to you to remember as we're moving forward.

We are looking for more of a self-administered program, so person-directed planning, to understand what Mitchell is going to be doing with his day. We may actually choose agency services, as was discussed just previously, but we want to have the choice. We know that there are great people in all different realms, whether it's Mitchell's circle of friends or within the agencies that currently support us.

We receive different buckets of money, so we're trying to manage which form to send in for which monies to make sure when—sometimes one bucket is empty and the other one's not, so then we have to redo the forms. We receive some funding hours right now through CCAC, our supporter, again, on the health care side—a personal support worker. One Care, who is our local support agency, does not have pediatric workers in the town of St. Marys who can fulfill his hours when we need them filled. Our workers probably like to work more with seniors and not with pediatric, challenging, physical little boys. We have had the opportunity to actually outsource those hours to Community Living St. Marys, and we now get supported through them. Before that happened, we were leaving hours on the table because we couldn't find people to actually work those hours, and we didn't have the ability to have our own worker come in and do that, the trusted circle of support that we have for Mitchell, because of those monies being enveloped.

The other perspective that I heard today, and again, it's in my guiding principles on the last page, is one person, one funding. I look at all the different envelopes and how much time and overhead we have within the ministries related to managing this one person. We need to look at their lives as a single entity and try and support them better that way. When I look at all the different agencies that end up supporting us and the management that goes into those very few hours that we get, I wonder how many other people or Mitchell could get a few more hours because of that extra management that's involved with that.

I'm going to shift a little bit to education, because that's where Mitchell is right now. He's in a grade 3 classroom. I sat on SEAC through two or three budgets with them in Seaforth. It's very key, especially in the boards with declining enrolment, that the special education funding formulas aren't working. We need to have more of a student-up planning process versus a random formula-down approach that you'll see with the SEP and the high-needs amounts that are occurring. The type of children who are in the school system now are more

complex perhaps than they were before, and there's more of them. There are more different diagnoses that are happening—as well as those who aren't specifically diagnosed who are receiving special education supports. Even things like tutors to help the general population are sometimes coming out of the special needs education program, which I think is a great thing because it helps overall education levels to be higher-achieving. For Avon Maitland, I was speaking with our superintendent last week, and she indicated there will be about \$700,000 over their special education envelope this year for providing special education services.

There's a real groundswell with parents around access to curriculum. Our kids aren't going to school to be babysat or to learn life skills; they're there to access the curriculum. We need to support our teachers to ensure that they understand how to accommodate their curriculum to reach every student in their classroom. Challenges with having the right EA support, should an EA be the one that has been selected through the process to support our children—to make sure that they fit the learning profile and the physicality required of the job. The staff selected are not always able to manage the child effectively. Again, I look to Mitchell, who is an eight-year-old boy, very strong. We need to make sure that we have someone who can successfully manage his school experience and the safety of him and the others while doing so. That needs to be paramount over the desire of who wants to be in that building. I'll say it that way.

From a SEAC perspective, if you look at the membership requirements: Parents are specifically excluded from participating on SEAC. You need to be part of organizations to sit. I sat because I was the chair of Parents in Perth; that's how I got in as a parent. If you want special education to be accountable to the children, have a few parents sitting around the table to talk about how special education is being delivered in their school boards, and the conversations will be very different. The associations I sat with were amazing, but I think, as we don't go to talk about our specific children at those tables—we talk about experiences and how their funding choices are going to be delivered and how that will impact school experience. I think that's another thing that you need to perhaps look at: changing up the selection criteria for that committee.

1110

On a positive note—so what's working for our school board—we are going down the path of full inclusion within Avon Maitland. They are closing their segregated classrooms. It's a slow process. That's the vision of the board, certainly, working from elementary school up through to high schools and working through those challenges. My comment to that is, how can we assume full community participation if it's not how we teach? Our school board has been very good. Our specific school has been exceptional, since it opened in 2010, on building an inclusive community.

Again, it's not documented research, but Mitchell's diagnosis is that he is non-verbal. He has learned so many skill sets related to speaking and verbally com-

municating, it is amazing. People who come in and re-test him for his Special Services at Home, his application, say how amazing he is with his language skills. That is directly related to the fact that he is in an inclusive classroom. His peers in the US system, where they prefer—some of our parents are preferring special education schools. Their children are not having the same verbal experience that Mitchell is having. I put that totally to the kids. It's not to the parents or to the speech consultants. We help. It's the kids.

The Chair (Mrs. Laura Albanese): I just want to let you know that you have about a minute and 15 seconds left.

Ms. Lynn Hainer: Okay. Well you have the rest of my presentation.

What I really wanted to talk to you about lastly was the DSO. We are not at the level of needing to go to DSO yet, as Mitchell is eight, but I believe strongly that our kids, specially kids as complex as Mitchell—we have the test results, DNA, that tell us what our kids have. We need to be spending the time in understanding the needs of those who are on the margins. Spend the time with those families who really need to figure it out.

We have been in the system, again, eight years; others have been in 18 years by the time they get to the DSO. It's not adding value. I concur with the other comments that the \$12 million that is being spent on the DSO should go directly into services and that fully funding the system is what is required to ensure we start moving beyond this gap.

The last piece I want to just quickly talk about—that's with my municipal hat on—is around housing. We have housing and homelessness plans that are coming in. If you, at the provincial level, are really auditing that they are meeting the needs of their community, so options for housing around people with intellectual disabilities—when that ministry came and spoke to you, they indicated that they had no specific plans or requirements to segregate out how they manage that participation group within their own sector. Make sure, when those plans are coming in, that we are addressing those. We need to have funding envelopes that don't include building housing, that will have choices where they're living. Sometimes their disability does not allow them to live in those congregated social housing projects because of the noise, smells and everything else that makes it unsuitable for them.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your comprehensive presentation. Thank you for introducing us to Mitchell and for the very valuable suggestions.

—MS. DIANE WHITE

The Chair (Mrs. Laura Albanese): We'll now ask Diane White to come forward. Again, you may begin whenever you feel ready.

Ms. Diane White: Thank you. Good morning. My name is Diane White. My husband, Dave, and I live in

St. Thomas, Ontario. Together, we're raising two sons, Alexander and Aidan. While they both have developmental disabilities, our Aidan is my reason for speaking with you here today.

I'm just a mom. That's all I am. I'm going to share my story and a day in the life of Aidan with you for my presentation. This is so you may come to understand the parental commitment and the need for support in raising a child with complex needs.

From the moment Aidan became our son, I gave up my banking career and began to focus on his care and on striving to assist Aidan on his journey to achieve his potential and to become the person he is meant to be. Immediately, I sought out supports and services through early intervention and support groups. I quickly learned, though, how to advocate for his needs, becoming a medical and a developmental expert. Aidan has had major surgeries, including open heart surgery and the removal of a cataract from one eye. I learned to ask the important and sometimes really hard questions, and I expected the respectful answers from professionals. Sometimes I was successful and enjoyed a positive relationship with doctors and therapists, and other times I became discouraged at the lack of knowledge and/or co-operation. But I never gave up.

When Dave's career afforded us the opportunity to move to different cities throughout the years, each time I started over, seeking services and support groups. Where there were no support groups available, I connected with schools and classmates of Aidan's or Alex's, and started and facilitated my own local support groups.

Currently, I co-facilitate a support group, the Sharing Network for Challenged Kids, in St. Thomas. I assist other families in procuring any services to which they and their child are entitled. I volunteer within our community as a mentor and as an advocate for any family who requires it.

My husband and I, together with two other families, have founded and incorporated a not-for-profit business called Elgin Active Living Centre, which was referred to earlier today. Our vision for this project is to raise the funds to purchase one of the local closed schools and convert it to a residential facility with attached 24/7 supports and a day program. This facility would house approximately 12 to 16 young adults with various needs, with developmental disabilities, regardless of the cause of their disability, whether it was Down syndrome, whether it's autism, whether it's fetal alcohol spectrum disorder, with developmental or intellectual disabilities. They would have access to supports, as much or as little as they would require to be successful. But EALC is another story.

Aidan was born with Down syndrome, a congenital heart defect, a bowel blockage and a cataract. As one doctor who met us declared, Aidan seemed to have got the Cadillac version of Down syndrome. Over the years, we've been welcomed at Ronald McDonald homes in both Toronto and Hamilton as Aidan has undergone corrective surgeries. We have met and worked with top

ophthalmologists from the optometry department at the University of Waterloo. We've had to seek out the services of dental specialists, gastrointestinal surgeons and hematologists. To say that Aidan has successfully fought and recovered from all of his medical conditions would be an understatement. But then, at age eight, Aidan was further diagnosed with autism.

To sum up my son's conditions, he has Down syndrome, autism and gastrointestinal concerns, is prone to skin infections, and is blind in one eye. He requires care, supervision and support 24 hours a day, seven days a week.

I'm going to now share with you a typical day in the life of Aidan. I'm not going to go into policy. I'm not going to go into—I have a solution at the end, but I think you just need to hear my day with Aidan, or Aidan's day with me. This is typical.

As you can imagine, school currently takes up a good portion of his day, and he is gone, on a school day, from the house for six and a half hours.

Aidan struggles with falling asleep, so most mornings I need to wake him up. I get up at 6:30. I go in, I wake him, and he's grumpy. "No schoo. No schoo today for Aidan, stay home, Mommy," he says. And every day, I call his bluff and I tell him, "It's great. You can stay home with Mommy." We go back and forth, him saying he doesn't want to go, and me saying, "You can stay home." And then all of a sudden, he says, "Mom? Mom? Mommy? Go schoo today?"

So, finally, about 10 minutes into our morning, I can get him out of bed and take him to get toileted. He cannot do this himself. Our conversation during that time is all about his routine for the day, starting with his all-the-time, every-day breakfast—waffles—except on weekends, when it's pancakes.

1120

He goes through his day, pausing after each activity to await my verbal "yes" in agreement. If I don't respond with that "yes" and nodding, he continues repeating it until I do respond, only to have to start all over again. We do this about five to six times, until he's ready to be dressed for the day. Aidan has sensory issues, which means each article of clothing must pass his inspection. He doesn't care what they look like; he cares what they feel like on. I dress him in his approved clothing. He cannot do this himself.

Off we go to the kitchen, where he bounces on his exercise ball while I make his waffles and pour his milk. He cannot do this himself. I cut the waffles into bite-sized pieces on his plate and give him a fork, and he sits eating, using his fingers. While Aidan is eating his breakfast, I make his lunch for school, and it's always the same: chocolate milk, two yogurts, two puddings, a small container of crisps and a thermos of chicken noodle soup—the smell of chicken noodle soup in the morning is really starting to get to me, I have to say—but he cannot do this himself.

Once his breakfast is done, I wash his hands and face and brush his teeth. He cannot do this himself. We go to

the front door, and I put on his socks and his shoes or his boots. He cannot do this himself.

The bus arrives at 8 a.m. at the end of our driveway, and I walk him to it, to his waiting monitor, so he won't run away or onto the road. Boy, can those six and a half hours that he's at school go quickly—although many times it's not six and a half hours; sometimes it's less than an hour. Our school's staff is wonderful in his program, but on those days when Aidan is unable to appropriately behave or to successfully interact with staff and peers, I need to be called upon to come and get him.

His day at school is very structured. It's very predictable for him. Unfortunately, it can become boring for him sometimes, but when we try to change the routine and the predictability he can become combative and non-compliant. It's kind of a Catch-22 situation. I have also had to seek out the option of a day program where his need for one-on-one support results in a weekly fee of \$850.

Aidan's bus brings him home by 2:30, and I need to go out and get him off, but before he'll get off the bus we need to go through the remainder of his day, as we discussed it in the morning. God forbid there's a change—maybe I'm not making something that I said I was for dinner, or maybe one of his support workers is ill. That will make him not even get off the bus, so I lie about whatever I have to.

Once off the bus, he may walk with me up to the house and come in, he may choose to run out onto the road or he may even decide to sit down in the middle of the driveway—it doesn't matter what the weather is. When he sits down, he refuses to get up for at least 15 minutes, and no amount of cajoling, begging, pleading or bribing will get him up until he decides.

Once in the house, I remove his jacket, boots and socks. He cannot do this himself. Then it's a trip to the washroom again and using his vacuum—yes, his vacuum. He received his own for Christmas and loves to stand with it on, making the same sound as it, so I plug it in and I turn on his vacuum. He cannot do this himself.

French fries at supper are Aidan's idea of vegetables, and they're served on their own plate with a dab of ketchup. The other plate is reserved for the meat—and, of course, ketchup. Aidan loves chicken: beef-chicken, turkey-chicken, ham-chicken, fish-chicken or just chicken. As long as it has the name "chicken" in it, he will eat it. His food is cut into bite-sized pieces. We give him a fork, and he uses his fingers. I pour his milk. He cannot do this himself.

Aidan is showered and shaved every other day. I turn on the shower for him, adjust the temperature, undress him and help him into the shower. I wash and rinse his hair, I scrub and clean his body, and I foam and shave his beard, sideburns and moustache. He cannot do this himself. I rub him dry. He sits on my lap. I dress him in his pyjamas and dry his hair. He cannot do this himself.

At bedtime, he has a whole routine of juice, jammies and songs. When that's done, he lays down for hugs and kisses, goes through tomorrow's routine, is assured that

it's not raining and not thundering out, and is tucked in. Within five minutes he's up again for the same discussion: the routine tomorrow and whether it's raining or thundering. He wants a drink and has to go to the bathroom. We talk to him and send him back. He's up again within five or 10 minutes. For all of those same reasons, it generally happens eight to 10 times a night.

Finally, about an hour and a half to two hours after we start, he is asleep. Most nights, he wakes several times through the night, and he parties and sings. He doesn't want you there. If you walk in, he looks at you like, "What are you doing?" He just wants—he's just awake. Then, at about 6:30 the next morning, we start all over.

Aidan does not participate or co-operate in any of his necessary health care. He is physically resistant to any kind of medical or dental intrusion into his personal space. That means that for any ordinary physical or dental examination, he has to be sedated. He is unable to take oral medication, which means hospital trips for even simple antibiotic injections.

Travelling with Aidan requires careful and thorough planning and support as he requires a pushchair for the safety of himself and others.

We have been in crisis as I became ill and attempted to access an emergency bed for Aidan. At Regional Support Associates, there's a waiting list.

Now, imagine I'm one person doing all of this, or imagine there's no school for the day, or imagine I'm ill, and understand that Aidan is nearly 19 years old, and I've been doing this for all his life. Fortunately, for my family and our Aidan, I have the ability to advocate effectively, to speak to decision-makers and policy-changers.

I have somehow managed to find the time and the energy to devote to case-managing my son's life. I have been loud enough to have successfully obtained some sustainable, I hope, funding to support Aidan as he awaits an appropriate residential placement.

I have two wonderful support workers who assist Aidan in the community for approximately 24 hours a week, but we have no weekend respite. We have no overnight respite. There is no transition planning available to families anymore. There is no case managing or facilitating. There's no crisis intervention.

The current model of service delivery is, in a word, unsatisfactory. The new Developmental Services Ontario had the potential to be a great centre for assessing, centralizing and delivering service, but instead it is only a gatekeeper for all wait-lists for all services—simply a middleman.

We keep being told there's no money in the system, yet agencies are developed or expanded. People are hired. No one, from front-line workers to managers to executive directors, has the ability or mandate to truly help our families.

We need a permanent solution in the form of a non-partisan committee or corporation that is sustainable and constant throughout each provincial election, no matter the governing party, that transparently oversees the delivery of services in a fair and equitable manner. This committee or corporation will be responsible for ensuring

delivery of any and all services and supports required by our special population.

The ministries directly answering to this committee or corporation would and should include the Ministry of Children and Youth Services, the Ministry of Community and Social Services, the Ministry of Health and Long-Term Care, the Ministry of Municipal Affairs and Housing and the Ministry of Education.

Transitions from children's services to adult services need to be seamless. Ministries and agencies need to stop forcing parents to once again prove their child's disability in order to qualify for adult services.

I am sad, I am tired and I'm broken. My greatest wish is that we can find a wonderful and supportive place for Aidan to live and thrive and be happy in. My greatest fear is that Dave and I will not be healthy enough, or maybe even not around, to ensure that this life-changing transition for Aidan is the positive and joyous one he deserves. He cannot do this himself. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for sharing your story. We have about a minute and a half for each party for questions, and they start with Ms. Taylor.

Miss Monique Taylor: Thank you very much, Chair. Thank you so much for your presentation today. Thank you for bringing Aidan here to share him with us and the life that you live.

I'm curious, as the other speaker spoke about the Elgin Active Living Centre: Where are you in that process, and is it working? Are you getting stopped? What's happening?

1130

Ms. Diane White: We were stalled because of crises in my family, crises in Sue's family, crises in the other family. When you're dealing with your own personal crises, as much as your heart and your mind want to help out in the community, you're stuck. I became quite ill and just couldn't manage it. But we are trying to get back together and find a direction. We've done a budget. We've had Tom McCallum from Community Living Elgin mentor us. As Susan indicated, we've spoken to Jeff Yurek, our MPP. Christine Elliott came and met us on occasion; and Joe Preston, our MP locally. We've talked to different people. We need to find someone who will give us direction at this point. We have ideas, but we need some direction and some guidance to bring it all together. We have the passion, we have the vision, but perhaps collectively the six of us adults don't have the skills to really bring it to fruition on our own.

Miss Monique Taylor: So—

The Chair (Mrs. Laura Albanese): Sorry; I'm going to have to move it on. I apologize.

Ms. Wong.

Ms. Soo Wong: Thank you very much for sharing your story with us today. I listened intently to the concerns about the—this is not the first time we have heard about the desperate need for respite. Can you share with us, in terms of your research—obviously, you've done a lot of homework on this file—where are the best practices when it comes to respite care across Canada or elsewhere?

Ms. Diane White: I think BC has definitely led the foray in developmental services across the board, whether it's inclusion, whether it's education or whether it's support and respite. I've lived in Chatham-Kent. They had a wonderful respite home for children that was accessible seven days a week. I don't know if it's still there, but it was wonderful for the families to be able to access it. There was co-operation between Community Living, Chatham-Kent and the school board so that for any individual who was in school and stayed at the respite home for the week, the bus would still come and pick them up there.

When we moved here, there was nothing like that. Eventually, they came up with a children's respite home that serviced two children under the age of 18 every other weekend. That's all. It was not even accessible.

When I went into crisis, we were given a sum of emergency funding and we were able to access the respite home for Aidan even though he was an adult because it was sitting empty every other week. Again, that was \$2,300 if he went to that alone. That respite home has since been closed and is being turned into a group home for four transitional youth who have, under the government's guise, already been on the radar, but there were no plans made for them to transition out of their child group home residential placement into an adult one. Now, as a result of that lack of planning, Elgin county has lost its only respite home.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Elliott.

Mrs. Christine Elliott: Thanks very much, Diane, for coming to present to us today. I think it's really powerful, telling us Aidan's story and what a day in the life looks like. I've also had the pleasure of meeting with you in St. Thomas, as you mentioned, and hearing more about the Elgin Active Living Centre. I think you really underestimate your own talents and abilities and those of your group. It seems to me that you have a wonderful plan. Really, what you need now is just a capital investment in order to be able to buy the building. I think you know very well what you want to do with it.

I do have some additional information that you've shared me with. Would it be acceptable to you if I shared it with the other members of the committee so they would have a more complete understanding of what it is that you have in mind?

Ms. Diane White: I would love that. Absolutely, yes. Thanks, Christine.

Mrs. Christine Elliott: Thank you. I'd be happy to do that. We're happy to help you in any way we can.

The Chair (Mrs. Laura Albanese): Thank you for presenting to the committee today. It was lovely to meet you and Aidan in the picture.

Ms. Diane White: Thank you for the opportunity.

COMMUNITY LIVING ST. MARYS AND AREA

The Chair (Mrs. Laura Albanese): We'll now call on Community Living St. Marys. I believe we have two

people presenting, Vickie Logan and Harold Holland, if I pronounced that right. Please take a seat. Feel free to start whenever you feel ready.

Ms. Vickie Logan: Good morning. I am Vickie Logan and this is Harold Holland. It is our honour to represent families from St. Marys and area who have met to discuss the challenges we see in the developmental sector as it is functioning at this time.

Two families could not join us today. The teenage son of one family has undergone another surgery. The father in the second family threw out his back and the mother must be home with her adult son.

I am the mother of a beautiful 29-year-old—her name is Robynne—who, at the age of three, was the 38th diagnosed case in the world with her particular developmental delay. There are currently 70 people in the world diagnosed with this delay. We were told that she would never walk, never talk and would invariably fall behind, but if we wanted to try and teach her—"Go ahead, blaze a trail."

So that's exactly what we did. She walks, talks, sings really badly, can read and spell a bit, can do simple math using a calculator, and is a known and loved volunteer in five communities.

Many of the things families take as commonplace now, we fought for. They were new and extreme for the time, but we were able to enlist the help of people along the way who saw the potential that sparkles from Robynne's eyes.

Robynne lives at home with her dad and me. She was granted a lump sum of money when the Passport Program was initially established. It was not based on a support budget and does not come close to meeting the actual support that would enable her to fully realize her dreams and meet the established goals. Still, we do the best we can with what we have, trusting that one day there will be a change in the system.

I am also the accountant at Community Living St. Marys and Area. Our agency provides individualized supports, creates individual budgets and produces individual income statements each month. When I speak to you today, it is backed by being the parent of someone receiving support and having worked for the agency providing that support for 20 years.

Mr. Harold Holland: Hello. My name is Harold Holland. My wife and I adopted two children, one at age 11 months, Aimee; and then three years later, we adopted a little boy named Thomas.

As the years went on, it turned out that both had special needs. Aimee is now 27, with borderline personality disorder. We've had to break communication with her. She became a ward of the court. She's now living in a group home in Exeter.

Thomas is now 23. He's been diagnosed with autism, Tourette's, developmental delay and anxiety disorder. He has full-time support 24 hours a day, seven days a week.

My wife didn't work when Thomas first arrived. She spent most of her time in the next 20 years running children to appointments, seeing specialists, therapists, school meetings, advocates and supports.

I may be at the wrong meeting, because we have funding. We've received funding and supports from Community Living St. Marys and Area, family services, CPRI, RSA, the Crest centre and numerous professional specialists—all this coming through crisis emergency intervention. I could go into telling you the story of Aimee and Thomas, but it would take a half a day for each child.

All this money that's been spent on Thomas alone is mind-boggling, but it's all been worth it. He's a happy guy, and for the most part, he's a lot of fun to be around. He got a job in November. He's got a purpose in life now. He's a happy guy. He's had a great year with his support staff.

But what I'm afraid of is, why do we always have to go to a crisis to get to this part? I know several families that are raising their children—and some of them are adults—at home, thinking that things will work out. I worked with Perth parents, and we sat down and wrote letters to the Ombudsman. It was amazing the people who didn't want to tell their story; it's amazing the people who couldn't write a story. We helped them with that.

As the parents age and the children become more difficult to handle, and there's no routine once school is over, it gets complicated. It takes a big physical and mental toll on the supportive parents, the staff and the child. What ever happens when the caregiver cannot give anymore? Is that, then, a crisis? I feel that these people who I know are all time bombs just waiting to go off.

Ms. Vickie Logan: The concerns raised by the families in St. Marys include the acceptance of waiting lists as being the norm; no affordable housing options; young people being placed in nursing homes; the cut to special services at home at 18; and the increasing disconnect between the system and the people it was established to support. Families are in crisis.

1140

The current system is deficit-based. We believe that a more positive system based on potential—their hopes, dreams, goals and achievements—would be far more valuable to the people using support services. A deficit-based system drives down the perceived value of people and creates the impression of handouts rather than hands up. Imagine how you would feel if every day of your life you were made to think negatively about your child, to see all that is wrong with him in order to secure the supports they need to connect to their communities—communities where they can make friends, have jobs, make real contributions to society and teach those around them about respect and acceptance.

Current access to funded developmental services is through the DSO, as you know, and involves a long application and assessment. We spent six hours doing a SIS assessment and received a useless multi-page document that provides no information about Robynne. It sits in a file drawer in our home, and a copy is housed in the DSO computer. There is nowhere for her to go because there is no funding entity established as part of the

transformed system and no hope of securing the funding to obtain support. We are wait-listed.

Some of us are being asked to have our children get further psychological testing to determine eligibility. This does not make sense for many people who have been identified with a lifelong disability. There is a huge cost both to families and to government. The Ballantyne family has had to make numerous inquiries and arrangements for testing their son Mac, when even the DSO assessor knows he is eligible. This has added huge amounts of stress to an already very stressful situation. Mac is turning 18 in August, and the funding received now for his support will not be available once he turns 18. Added to the threat of no support, Mac has just endured another surgery related to his physical disability due to cerebral palsy.

Wait-lists contribute to the feeling of scarcity and hopelessness. There are very real crises among aging parents with adult children still living at home. No one would argue the point that these situations must be addressed immediately. However, with the cut to SSAH funding at 18, the system has now created a greater base of crisis situations.

Often overlooked is the group of parents who are not in the aging category. We are in our forties and fifties, but our daily stresses are the same as everyone else's. Plus we fear for the future of our children, and we know that we limit their ability to connect to community. We can't work, be parents and be the support workers for our children. We also have elderly parents who are often our support network and provide the breaks we need to get through another year. Some of us are the sandwich generation in that we have elderly parents to support and adult children to support. Matthew lives outside of St. Marys on the farm with his parents. They provide for all but a few hours of support each week, and they provide a home and support for his 90-year-old grandma. There are no other families in the area, and Matthew's parents are tired.

There are few alternatives for families. If there is no support in communities, some people are forced to look at the health care system. A number of young adults have spent months in Perth county hospitals—not because of health-related issues, but because they had nowhere else to go.

As well, young adults are being placed into nursing homes. This is horrific. They will live out their days with no connection to their communities at all. While their base needs will be attended to, they will not have full lives. Once again, we are limiting their potential and neglecting all that they can contribute to society. There is a cost associated with young people living in nursing homes. Why can't this money be used to support them in their community?

Families are also turning to police services to support them in crisis. Often, as Harold mentioned, crisis can be avoided if adequate supports were in place for families. The Dunseith family feel little hope for their future and for their 36-year-old son who lives at home. Until some

secure funding for support is made available to their family, they fear for their safety.

Planning for life, including times of crisis, is key to supporting our children to live full and contributing lives in the community. Person-directed planning, and the facilitation and funding needed to implement those plans, will prove to be a smart investment. Our children, young or adult, and our families want to expand possibilities in the community, but we need help. New legislation allows for person-directed planning, but this service is not funded in our system, and it needs to be.

A person's life does not need to be divided into funding categories. If we are able to get some funding as a family, we end up trying to track it and keep it all straight, and it's really quite confusing. A life is a life, whatever support a person requires to live it in a dignified manner and to achieve their goals.

As parents, we're not looking to abuse the system by getting our hands on unreasonable support dollars. We all know what it's like to sit on a waiting list and how it feels to have no hope. We do not wish this on anyone. Providing lump sums of money not based on a real support plan does not solve the issue. You need to trust that we will use the funding as efficiently and as effectively as possible. We will do what we know is right for our children and continue to be creative and progressive.

By investing in the potential of people, helping them to be in their community, living, working, volunteering or joining groups, we provide them with the skills that they need. We help them to realize the importance of rising to what is acceptable behaviour, about their appearance and the rules of society. We give them the skills they need to live as independently as they possibly can so that, when it is time for them to move from their family home, they have already established the connections and the skills that they can build on to grow. They have people around them who already know them and care about them, so the transition is eased.

Robynne showed a window of time which would have been ideal for her to move out of our home, but we could not act on it, so she remains. With each passing day, that window closes more, because she becomes more comfortable and she is losing that drive for her independence from us. But what happens if she is still at home when my husband dies from the number of life-threatening physical problems he has? What happens when I die? Robynne's home will be sold out from under her. Her family will be gone. She will lose everything and have to try to begin a life during the very time she is grieving for all that she has lost, trying to understand something that none of us is good at understanding. As her parents, we fear that day, because we know that there is no money to provide the support she will need.

It is our hope that you will truly hear what we are trying to tell you today and that real, systemic change will result from the time that we have all taken.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We have about two minutes for each

party. We will start with the NDP. Miss Taylor or Ms. DiNovo.

Miss Monique Taylor: Thank you so much for your presentation and thank you for the work that you're doing in the community and for being an advocate for so many families. We can tell by your presentation that you're definitely in touch with your community, and you see what's working and what's not working.

I would love to hear your opinion on the DSO and whether you think that it's something that should continue or something that should be changed into working for families.

Ms. Vickie Logan: I think that the DSO has got too much power. Without the funding entity, our transformation didn't really have an end plan. It just started throwing things into place without a global idea of how things were going to look in the end. The DSO says that there's no money, and they're right. There's no funding entity doling out money to anybody based on anything.

I think that it's a layer of infrastructure that could be better spent supporting people in the community.

1150

Miss Monique Taylor: Thank you. If you had a magic wand, what would it be used for?

Ms. Vickie Logan: I would invest in the people we are supporting. That's why we all have jobs in the first place. That's our reason for being. Our reason for being is not so that we can sit in nice offices and have the latest technology. We're here to support people. That is our only reason for being. To build an infrastructure that serves no purpose is kind of like—remember that analogy where the guy was hired to run the well, and he was the guy who got laid off, but all the infrastructure was above. I feel kind of like that.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. I will now ask Ms. Wong to take the microphone.

Ms. Soo Wong: Thank you very much for your presentation. I was reviewing your written submission to the committee. One of your recommendations—you asked to reconsider the lengthy application assessment process. Can you elaborate on what you said here, the collection of some of this information? What are examples of some of the information that can be less costly? Can you give us some examples of that?

Ms. Vickie Logan: I think that most of you—sorry. Do you want to answer?

Mr. Harold Holland: Go ahead. No.

Ms. Vickie Logan: I think that most of the people in the province have had every test available that they can have on their children. I don't think you need to do them again. You might need some updating, but I'm pretty sure the parents are going to be open and honest with you about how far along their kids have come.

I'm proud of everything that we've accomplished. We've worked hard. I think we've done a good job. I'm not going to undermine my daughter for an assessment. I think those types of things money doesn't need to be spent on, unless there are huge dramatic, changes in the person.

Ms. Mitzie Hunter: I'd just like to ask, in terms of providing her with the choice as an adult, what are the supports that would be required at that stage of her life?

Ms. Vickie Logan: Well, I'm hoping I've done as good a job as I think I have in getting her ready to live independently. My grand plan would be that she owns or rents a home in the community and somebody comes in and provides the overnight monitoring, maybe for a reduced rent or whatever—whatever can be arranged—that she actually becomes part of their life, part of their social structure and connections, but that it is her home. And if that person doesn't want to do this anymore, if they don't want to live with her, they leave. They take their stuff. But her house stays intact and she's in control of that. Because it's very hard to keep control over your life when everybody's telling you what to do and everybody's telling you when to do it; right? So that would be something for her to be in control of, to be responsible for, to be proud of.

Mr. Harold Holland: She wants what my son's got. And it wasn't easy for us to get it, either. The paperwork is over the top. It's way too complicated to get funding.

The Chair (Mrs. Laura Albanese): Ms. Elliott, do you have any questions, or Ms. Jones? I just saw both of you going towards microphones.

Mrs. Christine Elliott: Such a great presentation.

Ms. Sylvia Jones: Vickie, Harold, thank you for your presentation. Harold, you're not in the wrong room, because, to your point, the reason that your son has been able to thrive and survive in the community is because you had to go through the crisis. And that's wrong, and we have to change that. So thank you for coming.

Vickie, in your last recommendation, which is 12, "Value the relationships developed in communities between people with disabilities, families, neighbours and community-based organizations"—great recommendation. I don't want to put words in your mouth, but my perception, anecdotally, is the DSO can be a block to that and has become a block to that. Can you comment on that? I don't want to assume that that's happened or is happening. Can you share your experiences?

Ms. Vickie Logan: You know what? For me, I like the idea of the community-based organizations, because we've probably grown up together. We went to school together. We went to church together. Well, some people went to church together. They did all these things together. Their kids grew up together. There's comfort in that. There are long-standing relationships in that. You can walk through the door and know that the person on the other side is going to be friendly. They're going to understand. They probably know a chunk of your story, so you're not going to have to rehash all of that, and you're not going to have to demean yourself by having to put that story out there. It's private and it's personal, and who wants to do it, really—right?

Ms. Sylvia Jones: Or try to make it sound worse so that you get to the top of the list, which is ultimately not what you're trying to accomplish.

Ms. Vickie Logan: The race to the bottom is kind of what they call it. But I think if you had a vision, an idea and a goal, how empowering that would be to the person sitting across the table from you. Sell the vision, sell the idea, get them on board with you and everybody is happy, nobody is burnt out and everybody is working towards something positive.

The Chair (Mrs. Laura Albanese): Thank you. Sorry, I am the tyrant with the time. I let it go over but I have to be mindful of the next presenter. Thank you so much for your wonderful presentation.

Mr. Harold Holland: Thank you very much.

REGISTERED NURSES' ASSOCIATION OF ONTARIO

The Chair (Mrs. Laura Albanese): We'll call now on the Registered Nurses' Association of Ontario to come forward.

Miss Monique Taylor: Chair, while they're getting settled could we ask research to possibly provide us with a copy of the application that families have to go through? I've seen it. It's quite intense and it takes hours to fill out. I think it would be good if we had a copy and could actually sit and go through it ourselves.

The Chair (Mrs. Laura Albanese): Certainly.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): Welcome to our committee this morning. You may begin anytime you feel ready to.

Ms. Kathy Moreland Layte: I'm as ready as I'll be.

The Chair (Mrs. Laura Albanese): Please start by stating your names.

Ms. Kathy Moreland Layte: Yes. Good morning. My name is Kathy Moreland Layte. I'm a registered nurse and professor of nursing from Kitchener, Ontario. I'm here today representing the Registered Nurses' Association of Ontario, the RNAO, along with my colleague, Mary Mueller, to my left.

RNAO is a professional association representing registered nurses wherever they practise in Ontario. Since 1925, RNAO has advocated for healthy public policy, promoted excellence in nursing practice, increased nurses' contribution to shaping the health care system and influenced decisions that affect nurses and the public we serve.

On behalf of RNAO, I'd like to extend our thanks to the Select Committee on Developmental Services for hearing our presentation today. Committee members are to be commended for addressing the issues of developmental services, as they impact greatly on the health of many Ontarians, their families and our communities as a whole.

Through review of the minutes of your proceedings, it has been noted that the issues of children and adults with autism and other developmental disabilities are being well represented. Thus I'll focus RNAO's remarks on a group of individuals and their caregivers who too often fall through the cracks of the developmental services

grid. I'm here to speak to you specifically about children, youth, adults and caregivers living with fetal alcohol spectrum disorder, and to share recommendations from the RNAO for you to consider. I will start by sharing some background information, which we have also included in the files before you.

Fetal alcohol spectrum disorder, or FASD, is a brain-based physical disability that is the most common type of developmental disorder in Canada. The brain damage developed in relation to FASD is permanent and cannot be cured. Because of their brain injury, people with FASD face a wide spectrum of lifetime challenges, from mild to very serious physical, mental and emotional disabilities.

Let me give you a sense of the disorder's key mental disabilities first. They include difficulty with assessment, judgment, impulse control and reasoning, poor memory and language processing, poor emotional regulation, an inability to generalize or think abstractly, and difficulty with planning and executive function.

The term FASD is in fact an umbrella acronym that encompasses four medical diagnoses, including fetal alcohol syndrome, or FAS; partial fetal alcohol syndrome, pFAS; alcohol-related neurodevelopmental disorder, ARND; and alcohol-related birth defects, ARBD.

This disability affects approximately 1% of the population. Equally alarming is the fact that FASD prevalence is only expected to rise. Statistics point to troubling trends. For example, binge drinking, defined as four or more drinks within a short period of time, is increasing. According to Health Canada, 20% of women of child-bearing age consume five or more drinks at a time once per month or more often. This is three times the rate of a decade ago.

Health Canada has determined that women at highest risk of binge drinking are 15 to 19 years of age, followed closely by those in the 20- to 24-year-old age bracket. Consider this: The Public Health Agency continues to state that no amount of alcohol at any time, of any kind, is considered safe for women thinking of becoming pregnant or for those who already are, yet the estimated overall rate of unplanned pregnancy in all women is 40%. The highest rate of unintended pregnancy is 82% among 15- to 19-year-olds.

1200

Let's get back to the disability itself, which is largely considered invisible. That's likely because those diagnosed with fetal alcohol syndrome, or FAS, are the only people under the FASD umbrella who bear the facial features so commonly associated with fetal alcohol exposure. A birth mother must binge-drink between days 7 and 15 of her pregnancy in order for those facial features to develop.

Others born with other forms of FASD go unnoticed until other symptoms appear. However, it is important to note that fetal alcohol syndrome is not indicative of greater or lesser brain injury than the other diagnoses in the spectrum.

Children and adults affected by FASD are at a higher risk of developing additional health challenges such as addiction and mental health issues, including anxiety and depression. They can have difficulties when it comes to learning and staying in school. Long-standing, unsupported attention to a child's FASD or lack of a diagnosis often progress into tertiary challenges such as trouble with the law, sexual promiscuity, unemployment, homelessness and other hardships associated with poverty.

In addition to the human cost of suffering for people living with FASD, there is great strain on health care, education, community and criminal justice services. Until people with FASD have serious behavioural or mental health issues, there are very few—if any—community supports available through the lifespan of those affected.

Let me now share the caregiver's perspective. There is a great deal of stigma associated with obtaining an FASD diagnosis, especially for a biological parent. Because of this, many children are instead diagnosed with attention deficit hyperactivity disorder, oppositional defiant disorder, attachment disorder or anxiety.

Getting an FASD diagnosis can take years. In Ontario—unlike Alberta, British Columbia and Manitoba—there are difficulties with obtaining a diagnosis, for three main reasons:

—There is limited diagnostic expertise. An FASD diagnosis requires psychometric testing—and a psychologist then interprets those tests—clinical expertise in management, a speech assessment and an occupational therapy assessment.

—The birth mother must admit to using alcohol while pregnant.

—Except for the medical services, a diagnosis of FASD is not covered under OHIP. This means an out-of-pocket expense for the caregiver, with the average amount of the cost of a complete assessment being approximately \$3,000 to \$5,000, compounded with the fact that it can take years to obtain.

Caregivers of children with FASD struggle, and often lose their children due to the aforementioned challenges. They have few options if they are living with an aggressive child, youth or adult at home; in fact, many caregivers often surrender their children suffering from FASD to family and children's services when they have no other support.

As the representatives from Peel shared in December, these parents are at the end of their rope. Children are also placed in section 23 schools not specifically geared to FASD issues, juvenile detention centres or group homes.

Because of funding cuts to regional and children's services, many group homes are closing under the auspices of inclusion and keeping families' children in their homes. As a result, many of those living with FASD are sadly lost to the streets, or families must continue to bear the burden of their child's aggression or needs.

Should their child stay with them, caregivers face a life of chronic stress and financial strain and grief as a

result of their child's disabilities and lack of educational and social support. Many caregivers report significant social isolation, exacerbated by a frequent lack of understanding of their child's issues from family members, health care professionals and educators. I would say that that's probably because these children look normal.

Many caregivers give up their jobs and face financial strain to stay home and care for their children, as they cannot be attended to at school. The high cost and lack of availability of trained caregivers, as well as the lack of respite opportunities, is a burden for many. Currently, families pay anywhere from \$15 to \$35 an hour for appropriately trained workers, and that's if they can find them.

Many of these children do not meet the threshold to qualify for supplemented care such as Extend-A-Family as they do not fall below the required IQ of 70 or the intellectual disability cut-off of 2% to qualify as intellectually disabled. Special Services at Home funding, while available, is limited to those who qualify. To make matters worse, caregivers of children with FASD have few financial resources available to them at all other than the disability tax credit—if, I would add, they're working.

Let me now address some of the issues related to education for people with FASD.

Many educators are ill-prepared to understand the needs and strategies to identify and assist those with FASD. While the Ministry of Education has already outlined the Education for All strategies, each school board must decide how their special-education funding is used. The funding formula is based on the 15% special-education criteria, I believe, set out by the Ministry of Education, but does not meet the needs of many communities. In my own community of Kitchener, over 20% of the children are identified with special needs. The board must deal with providing the best they can with the insufficient funds they have.

Cuts to educational assistant positions and child/youth worker jobs have made classrooms a difficult place for educators and for children with FASD to have their needs met. Inclusion philosophies have not considered the inability of many of these children to handle overstimulating environments. Children with FASD are often removed from school under the Safe Schools Act because of aggression and/or inability to cope with the sensory inputs of a regular classroom. Because many of them look normal, educators have more difficulty recognizing that these issues are a part of the disability versus defiance. Consequence-based approaches to problematic behaviour rarely work with these children, and they have little ability to transfer learning from one context to another.

Individual education plans and the Identification, Placement, and Review Committee—or IPRC—processes have many loopholes that allow school boards to limit educational assistant help and support and promote the concept of modified school days and/or removal under the Safe Schools Act when behaviour problems become

an issue. This creates a great deal of stress and financial burden on the caregivers.

While removed from school, there is little or no tutoring provided. These children are left on long waiting lists for limited and often inappropriate mental health services or classrooms that are often effective but short-term. These waits can last anywhere from months to years. The children are then returned to their regular schools, often for one to two hours a day, and then the cycle becomes repeated. Many caregivers eventually remove their children from school permanently, resorting to home-schooling because of exasperation and frustration.

It's also important to discuss the transition to adulthood for people with FASD. It's estimated that those living with FASD may be developmentally one third to half their biological age in many functions, putting them at great risk during their teen and early adult years. As a result, people with FASD require lifelong care, often in the form of a person or people to negotiate situations and prevent them from getting into difficulties in school, their teens and adulthood. At 18, children who were fortunate enough to have gotten diagnosed with FASD are eligible for disability, but have few or no social service supports to help them through the processes of the DSO, to get their disability support, to find work or to become self-sufficient. If they are still living with their caregivers, there continue to be no support services available. As you've already heard, aging parents and grandparents fear for their children's future in a similar way to those with other developmental disabilities. Who will care for their children if they become ill or die?

There are ballooning costs associated with the FASD population. The cost of FASD to the public is difficult to determine but has been estimated to be anywhere between \$1 million and \$3 million per individual over their lifetime; \$5.3 billion to \$7.6 billion is spent annually in Canada to support those with FASD from birth to age 53.

I would be remiss if I discussed costs without talking about the impact that the lack of care of children with FASD has on the criminal justice system. Based on available Canadian data, it is estimated that youth with FASD are 19 times more likely to be incarcerated than youth without FASD in a given year. Research also indicates that there is a 10 times greater incidence of FASD in the correctional population than in the general population. The average cost for a federal inmate in this country is roughly \$360 a day, or about \$170 a day as a provincial or territorial inmate. Compare these costs to the average cost of an early intervention. A child youth worker costs \$164 a day on average for one student, or \$82 a day for two students. Finally, an education assistant costs about \$123 a day, or \$62 a day if they have two students. Investing early shows greater changes of self-sustainability in the future for this population. To keep them in school is important.

1210

Let me now give you a sense of what RAO is doing to help those affected by this devastating disability.

In 2012, at RNAO's annual general meeting, a resolution was unanimously passed to address the prevention, diagnosis and treatment of FASD in this province. You have in your package a copy of that resolution, that was co-authored by myself and my colleague Mary, as well as some of the follow-up activities that have taken place, including an article from RNAO's bimonthly journal, *Registered Nurse Journal*.

In February 2013, RNAO released its political platform called *Why Your Health Matters*, and many of you probably met with members.

In an attempt to begin a conversation and prompt a call to action to leaders such as yourselves to collaborate and focus your work on matters that will build an even stronger province, our presence here today is a part of that commitment to educate you, as decision-makers, about this vital gap in developmental services for those living with FASD, and to advance healthy public policy to serve them, their loved ones and our communities. Lack of attention to people with FASD impacts on two of RNAO's key health priorities: accessibility to health care, and the reduction of poverty.

What can you do as political leaders driving policy in Ontario? I'll outline three points.

(1) RNAO is calling for a provincial strategy. We are one of the only provinces without a provincial framework to address FASD through an integrated, interdisciplinary strategy for prevention and diagnosis, and the care of individuals and families living with FASD.

In 2005, the Public Health Agency of Canada developed a framework for action on FASD, calling on all provinces to develop an integrated, purposeful approach to FASD.

To address FASD and save costly resources, Ontario needs to develop an evidence-based, integrated strategy. Such a strategy is currently being drafted for presentation to the provincial government by FASD Ontario Network of Expertise, which is called FASD ONE. Such a strategy would reduce the harm created by continued use of alcohol in pregnancy, diagnose early those affected by prenatal alcohol exposure, and provide support to individuals and families living with FASD through their lifespan.

(2) We urge that accessible, affordable diagnostic services be available to children who suffer FASD, and their families.

(3) Caregivers should have the respite and other services they need to be able to work, stay well and have a healthy family life.

In conclusion, FASD is a preventable disability, and Ontario is not adequately addressing it. Spending \$150,000 on prevention would save \$1.6 million in treatment.

Prevention is more than just raising awareness about the dangers of drinking in pregnancy. Addressing the inequities that exist in our province with respect to the social determinants of health, such as poverty and social exclusion, would significantly decrease the incidence of FASD. We need to promote the low-risk drinking

guidelines for all people in their childbearing years, develop policies that limit the potential for alcohol abuse, and involve all health care providers in screening for risky alcohol use and in education about the dangers of drinking above the low-risk drinking guidelines.

FASD impacts the health of all Ontarians, their families and communities, across all determinants of health. It creates poverty and secondary health issues while increasing costs to associated social services, education, health care, community services and the criminal justice system. It breaks families and entire communities.

The time for an integrated provincial strategy is now. With the focus on prevention, early diagnosis and the right supports, we as a society can decrease the prevalence and help those living with FASD achieve their potential. Without a provincial strategy, people who suffer with FASD—and their caregivers also suffer. The cost to the system in human and financial terms becomes greater. Individuals with FASD, and their families, need and deserve better.

On behalf of RNAO, I thank you for your time, and welcome your questions.

The Chair (Mrs. Laura Albanese): Unfortunately, we don't have any time left for questioning, but I want to thank you for your presentation. I personally learned a lot about FASD through your presentation. I admit I was not aware, in detail, of all of this, and I think that all other members found it useful as well. So thank you for coming and presenting to us today.

Ms. Wong.

Ms. Soo Wong: Chair, before we adjourn for our break, can I ask—because a couple of the last witnesses, their presentations, I want to follow up with the legislative researcher. Can I ask those questions now instead of waiting until after lunch? Is that possible, Madam Chair?

The Chair (Mrs. Laura Albanese): Is that possible?

Ms. Erica Simmons: Sure.

Ms. Soo Wong: Okay, so first things first. With regard to the FASD file, given RNAO's comments—and I dealt with this when I was on the school board. I need to find out why is it, in the faculty of education curriculum, there is no discussion or curriculum for teachers, incoming teachers who are going be trained at the faculty of education—there's nothing in the curriculum that talks about FASD. I know it's mandatory in the faculty of nursing, but it is not in the faculty of education, when given the data we just heard today from the RNAO—so I need some explanation of why is the College of Teachers not addressing this issue when they're in a classroom. That's the first question.

The second piece here is Councillor Hainer's presentation to the committee and her written submission on priorities. Can we get an estimated cost for one of her suggestions dealing with extending the Healthy Homes Renovation Tax Credit for eligibility for claiming the T2201 Disability Tax Credit? Can we get an estimated cost if the committee wishes to—

The Chair (Mrs. Laura Albanese): Make that recommendation.

Ms. Soo Wong: So I want to have a cost estimate.

The other piece here is on the presentation from Councillor Hainer to the committee—I don't know what page of the slides it is. She commented about SEAC, the parents not being eligible to sit on SEAC.

I know in the city of Toronto that is not true. I chaired SEAC.

The Chair (Mrs. Laura Albanese): It probably varies from board to board.

Ms. Soo Wong: Yes. So I need to know, because that is a legislated committee, why are certain school boards prohibiting parents' engagement in this provincially mandated committee and why only agencies can sit on SEAC. Why does the Toronto District School Board have parents sitting on the committee, yet here in Elgin county, the school board is different? When we have provincial legislation, isn't it supposed to be uniformly across? I just wanted some clarification about that piece. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. We have just received a package with ministry responses—

Ms. Mitzie Hunter: For the researcher as well, we've heard a lot of reference to the BC model. I was just wondering if you could share that with us as well.

The Chair (Mrs. Laura Albanese): If we could have some research done on that. Okay.

Thank you very much. We will adjourn, and we're adjourned until 1 p.m. We will return in the room at 1 p.m. Thank you.

The committee recessed from 1218 to 1302.

MS. SANDRA MOTHERSELL

MS. JILLIAN MOTHERSELL

The Chair (Mrs. Laura Albanese): The committee is called to order for the afternoon session. We welcome now Sandra Mothersell and Jillian.

Ms. Jillian Mothersell: Woohoo!

The Chair (Mrs. Laura Albanese): Thank you for being with us.

Interjection.

The Chair (Mrs. Laura Albanese): No problem. We welcome you to the committee and please, you can start your presentation any time you feel comfortable.

Ms. Sandra Mothersell: Okay. My turn first, Jillian.

Hello. My name is Sandra Mothersell. I am here with my youngest daughter, Jillian Mothersell. Jillian, her dad and I live in Grey county. Sue Near is present with Jillian to assist her with communication.

Jillian is 21 years old. She has a developmental disability. She has blue eyes and a beautiful smile.

Ms. Jillian Mothersell: Absolutely.

Ms. Sandra Mothersell: Jillian finished secondary school last June. In her first years of secondary school, she was fortunate to have Sue as a teacher. Sue continues to be a part of Jillian's life, and she assists Jillian to organize her thoughts with the use of a communication board.

Jillian is a strong advocate for facilitated communication because it has allowed her to share her deep thoughts—

Ms. Jillian Mothersell: And her deep breathing.

Ms. Sandra Mothersell: —and show her true potential.

Jillian is at risk of not being taken seriously by people who won't spend the time to understand her or allow her to pull her thoughts together.

Jillian really struggles with anxiety and lack of confidence. When she is feeling upset or nervous, her true personality is hidden. It is harder for her to communicate, to connect with other people and to stay present in conversations. She obviously feels very comfortable here today.

Ms. Jillian Mothersell: Yes, I do.

Ms. Sandra Mothersell: Jillian's preschool years were challenging. We were connected with a local Community Living behavioural expert to help with separation anxiety and issues with sleep and self-injury. The expert told us to continue loving her, and that was all that he could suggest.

We knew that Jillian needed more than love. We connected with CPRI in London. CPRI had a good outreach program at that time. The caseworker supported us and gave us the knowledge, tools and strategies to help us understand how important planning, routine, choice and control were for Jillian.

Skipping forward over the years of learning, planning, transitions, milestones and hurdles, as Jillian was coming to the end of her secondary school years, we realized that we needed to begin preparing Jillian for a future more independent of her family's supports.

Ms. Jillian Mothersell: Yes.

Ms. Sandra Mothersell: We began to read about the Passport Program and the plans to transform the developmental services system. The Passport Program was described as a program to assist students with a developmental disability who are preparing to transition to adult services and supports by promoting independence, fostering social, emotional and community participation skills. The transformation focused on promoting independence, dignity and self-reliance so that people can live and be included in their communities as full partners in society.

We were so hopeful and felt fortunate to live in a province that was creating programs and transforming to provide the future that we wanted for our daughter. We were willing to jump through all the hoops for the DSO assessment and the support intensity scale. We were emotionally drained by the end of this intrusive process that took 12 hours over two days, but we still had hope.

The Ministry of Community and Social Services started making announcements that were alarming. Although it did not affect Jillian, we were saddened by the announcement informing individuals and families that on April 1, 2012, Special Services at Home funding would end on the 18th birthday of those who turned 18 years of age after March 31, 2013. These young adults

would need to apply for adult developmental services and confirm eligibility. Many of these young adults were put on wait-lists instead of receiving the services and supports they previously received.

We thought about how important these formative years between 18 and 21 were for Jillian. We remembered how many new interests she developed in these years while she was supported in the community, interests that were not determined by the interests of her family. But we still had hope, and I argued that equitable supports and services would be provided based on the results of the DSO assessment. Other less naive and better-informed family advocates argued that no further assessments were necessary.

Over the past months we have realized that those advocates that argued against the assessment and SIS were absolutely right to do so. The realization came when we asked DSO the specific questions that the Ombudsman's office advised us to. The following reply from the DSO crushed our expectations. Here is their reply: "Jillian has been through the prioritization panel and would be considered to be in the moderate range. When there are available resources in the community in which she has applied, she will be given due consideration for resources meeting her needs."

We remembered all the assessments over the past 20 years that had assessed Jillian in the moderate range. How much money had been spent to come to the same result? As a toddler, planning, sequencing, organizing, problem-solving, reasoning, focus, fatigue, initiation, sensory processing and anxiety were identified as areas of difficulty for Jillian. As an adult, planning, sequencing, organizing, problem-solving, reasoning, focus, fatigue, initiation, sensory processing and anxiety are identified as areas of difficulty for Jillian.

It is time to realize that turning 18 years old does not make a developmental disability change. It is time to stop spending money on numerous assessments and end the wait-lists. It is time to further develop inter-ministerial co-operation that will provide seamless supports and services for health, education, housing, recreation, employment, transportation and community supports for life.

Each morning, Jillian wakes up and asks if she can go to Tim Hortons, swim—

Ms. Jillian Mothersell: And then—

Ms. Sandra Mothersell: —I'll just do mine and then you can do yours—or shop. She is so enthusiastic to help with breakfast club at the local school, keep her adopted road litter-free or support her great-aunt Lora on an outing. She needs one-on-one support to make all of these things happen. Without the natural supports of her family and the \$125 per week that she receives in Passport funding, she would simply watch TV all day.

I have been following along with the transcripts of these committee hearings. Many families have mentioned their fear for the future. One of the most influential people in my life is my aunt Lora. Aunt Lora is 83 years old. She has a developmental disability. I have the same

fears that my grandmother had many years ago. I saw my grandmother's fears become reality.

1310

After the loss of her parents, Aunt Lora struggled for many years, but she found a family home through the Family Home Program. Her family lived on a farm in a rural setting, similar to Lora's home in her younger years. Lora lived with her new family for 20 years.

You have had the opportunity to hear presentations from individuals and families. We will never all agree on one type of education, health care, support or residential option, because we are basing these decisions on our own unique lives and challenges. For example, some families self-administer direct funds, which they do efficiently and effectively. Others have found an agency that shares their values and philosophy. Our family self-administered Jillian's Special Services at Home and then Passport funds until very recently.

South-East Grey Support Services respects families and natural community connections. They welcome families to participate in supports and service decisions. They are now providing Jillian with opportunities to make choices and be supported as an individual.

Jillian has had the opportunity to have an independent facilitator and planner. We know that planning must be deliberate and independently facilitated to provide Jillian with the opportunity to have her choice in relationships, community participation, and volunteer and employment opportunities.

The outcomes of the independent facilitation and planning, with Jillian leading the way amongst the people of her choice, have given far more guidance and actions than the DSO assessment that has yet to serve a purpose.

With the adequate supports, Jillian has so much potential to be a contributing member of society. She advocates for a litter-free inclusive community with an increased understanding of acceptance and diversity.

And now it's your turn.

Ms. Jillian Mothersell: Oh, I—

Ms. Sue Near: I think my mom—

Ms. Jillian Mothersell: I think my mom is one great—

Ms. Sue Near: Woman.

Ms. Jillian Mothersell: —woman, and I really love her.

Ms. Sue Near: She has—

Ms. Jillian Mothersell: She has done something much—

Ms. Sue Near: Harder.

Ms. Jillian Mothersell: —harder than most parents have in the world.

Ms. Sue Near: That was spontaneous. Yesterday, Jillian wrote a piece using the same system, and she spoke out loud. We got it down in writing, so we're going to try to read it now.

Okay. But you can see, if she gets excited, it just causes some communication problems. So we'll just do the very best we can, right Jillian?

Ms. Jillian Mothersell: Yes.

Ms. Sue Near: Because I never—

Ms. Jillian Mothersell: Give up.

Ms. Sue Near: Okay. All right. Are you ready?

Ms. Jillian Mothersell: Yes.

I think my mom explains things better than I ever could.

Ms. Sue Near: I think my mom explains things better than I ever could.

But—

Ms. Jillian Mothersell: But she missed some things that I would like to do.

Ms. Sue Near: She missed some things you'd like to do, right? We came up with that.

Ms. Jillian Mothersell: Yes. I would like to continue to learn and to improve my communication.

Ms. Sue Near: She was my student. I've retired; I could not leave. We could not leave each other. I have a few students that I work with; it's incredible how hard she works and how well she does, so you can see why I couldn't ever let go.

Ms. Jillian Mothersell: I would never give up and I hope that the ministry appreciates how hard I try. I will not waste your funding, and neither will my friends.

Ms. Sue Near: Is that the truth?

Ms. Jillian Mothersell: Yeah.

Ms. Sue Near: This was her word coming up. I hope you can wrap your tongue around it. I was just so shocked when she said this yesterday.

Ms. Jillian Mothersell: My esteemed—

Ms. Sue Near: "Esteemed." I love—

Ms. Jillian Mothersell: Life.

Ms. Sue Near: And I love—

Ms. Jillian Mothersell: Language.

Ms. Sue Near: She loves language. She loves vocabulary.

Ms. Jillian Mothersell: My esteemed friend Christopher—

Ms. Sue Near: Christopher Wrigley.

Ms. Jillian Mothersell: —has shown me how important our work is—

Ms. Sue Near: How important our work is. He also said "world."

Ms. Jillian Mothersell: World.

Ms. Sue Near: I think she meant "world" when she was writing it: how important our world is.

Ms. Jillian Mothersell: We must show people that though we are different people, we are all intelligent. Am I doing—

Ms. Sue Near: Is she doing okay?

Interjections.

Ms. Sue Near: Okay. You're doing great.

Ms. Jillian Mothersell: We all wish to make this a better world for all of us. Each of us will do it in our own special way. It will be a great time when all people can be heard.

Ms. Sue Near: It's okay. You're doing fine.

Ms. Jillian Mothersell: I think Christopher would be happy if I read his words.

Ms. Sue Near: Did you hear her self-correct? Did anybody hear her self-correct there? She was reading along—okay. "I think Christopher would be happy if I read his words."

Ms. Jillian Mothersell: Thank you for getting—

Ms. Sue Near: It's okay. Mistakes are good. They can tell that you caught yourself.

Ms. Jillian Mothersell: —listening to all my dreams.

Ms. Sue Near: Jillian—

Ms. Jillian Mothersell: Mothersell.

Ms. Sandra Mothersell: Good work.

Ms. Sue Near: Christopher is a friend of ours and a member of—

Ms. Jillian Mothersell: The family network.

Ms. Sue Near: The family network. He is older than you are. He's 37 years old and he has been involved in adult services for a while now. I see him on a fairly weekly basis, and he tried so hard to be here. He wanted to be here, to be present. He's non-speaking, largely. He also uses a similar form of communication; he does it on a computer. He's eloquent. I would just love to share him with you. He's just a wonderful man, but I think it's captured in his writing. He has written oodles of things. He wrote this specifically for today.

"Dear committee members"—help me when I get stuck, will you, Jillian? Okay?

Ms. Jillian Mothersell: Yeah.

Ms. Sue Near: "I appreciate being able to add my thoughts to others representing self-advocates in Ontario. I have made a good effort to live on provincial allowances over the years. My mother is an excellent manager but has made huge sacrifices in order for me to live a healthy and stimulating life. In order for her to work, our only option was for me to attend a day program with others like myself. It had been adequate for many years, but services have not been maintained, with resulting loss of opportunity for community involvement. I would like my community funding to be released from Meaford Community Living. I would hire a facilitator to assist me and my family to develop a plan. This, I believe, is the expressed intent of the new legislation.

"Respectfully submitted,

"Christopher Wrigley."

Thank you.

1320

Ms. Sandra Mothersell: And in closing, I would just like you to keep in mind the value of the contributions of self-advocates, families and others that care when you make your recommendations. We ask that you make recommendations that allow us to be present and involved in decision-making at a provincial and local level, not as token representation but with honest respect for the crucial perspective we bring to the table. Please keep in mind that individuals and those that they choose to be present continue to be barred from meetings and decisions that determine employment and volunteer options, where they live and who they live with, how and by whom their health care will be provided, and how they

will participate in their community and who will support them.

In closing, I would like to thank the members of this committee for your respect for people with developmental disabilities and your dedication to an improved system. We have hope for an improved developmental service system because we know Jillian needs more than love.

The Chair (Mrs. Laura Albanese): Thank you for your amazing presentation, Jillian, and thank you to your wonderful mom and your wonderful teacher.

Ms. Jillian Mothersell: And thank you for all your hard work.

The Chair (Mrs. Laura Albanese): Thank you so much. You did great. Never give up.

COMMUNITY LIVING TILLSONBURG

The Chair (Mrs. Laura Albanese): Now we'll call Community Living Tillsonburg to come up. We have, I believe, three representatives here in the room. As you make your way to your seat, I just would like you to start by stating your name and your title when you begin your presentation for the purposes of the Hansard recording. Thank you.

Mr. Urbain Demaiter: Good afternoon, everyone. My name is Urbain Demaiter. I'm a semi-retired dentist. I've served on the Community Living board for a number of years, presently as treasurer. On behalf of Community Living Tillsonburg, we thank the select committee for the opportunity today to provide you with recommendations for the developmental sector.

Our organization has over 58 years of experience working with children with special needs and their families. Initially, we were organized by both parents and friends so that children with special needs would be able to remain in their communities rather than leaving to go to an institution. It is interesting to note that the government finally closed the last institution in March 2009. Through the years, we've continued to work with children through child care and child development programs. As the children grew into adults, we began to develop our supports and services to include adults. Our package provides you with our last annual general meeting report and brochures about our services.

We would like to make reference to the data report that we have provided in our briefing to you. This data has been provided by Developmental Services Ontario South West Region. The data shows that for the past year there were 1,098 requests for group living and 928 requests for supported independent living in the South West Region. Of those requests, 33 people were able to get group living supports and 42 people were able to get supported independent living supports. In Oxford county, there were 56 requests for group living and 79 requests for supported independent living. In Oxford county, one person received group living and eight people received supported independent living supports. Today in the South West Region, there are 1,457 families with children with special needs who are receiving Special

Services at Home funding. There are 942 families on the wait-list.

It was not that long ago that we used to see the wait-lists for supportive services at home eliminated or considerably reduced. We know that families are healthier when they get the supports they require and the respite they need. In our business case, we alerted you to the concern about growing wait-lists. We are prepared to take them on with you. You need to unleash the creativity of the community to address this crisis.

You provided us with a poster regarding employment a few years ago: "Don't Waste Talent." When people are placed on wait-lists and cannot access the supports they need, we are wasting their talents. We are placing people and families at risk when we, as a community, do not provide the supports we know they require. We are placing those families at risk.

We recommend that the government of Ontario recognize the dire need to address all service requests in a timely manner and seek the funding to meet the required needs.

As an agency, we experienced the strikes of 2007. We also saw what the strikes did to the individuals, and we have provided you with a copy of the booklet *Behind Closed Curtains*, which captured their feelings about the strikes. We recommend that the government not waste valuable resources by forcing strikes on our sectors.

In 2010, we were directed by government to negotiate reasonable contracts. Later, we were advised that these contracts would not be funded, as a wage freeze was being introduced. We have been managing these costs by reducing our staff. We cannot provide wage increases without government funding.

Unfortunately, our agency and our sectors get thrown into the broader public sector mix. There's a misconception that we have full pension plans and wages that reflect current pay standards in our society. We continue to be sectors that are still undervalued. We may achieve pay equity only if we self-fund it by eliminating positions and more services. This is not acceptable.

We watch as government tells us that the Ministry of Education needs new legislation to support the negotiation process between the three parties of school boards, unions and the government, yet we do not see the same concern with regard to our sectors. We remind you that over 100 contracts are coming due during the fiscal year 2014-15. Our past two experiences were not helpful, and we wonder what the experiences of 2014-15 will be.

We want to express to this select committee the need to rethink whether these homes are the homes of individuals or just workplaces. Yes, people work there, but the first priority is, these are people's homes; these people pay rent. We have worked hard at helping our staff recognize that it is the home of the individual. We have tried to ensure it as a home first and foremost and a workplace secondarily. We have seen the private member's bill around picketing at homes, and this might be one of the answers. We firmly believe that people should not have to experience strikes at their homes.

We also firmly believe that individuals need to have the right to choose who they live with. We cannot and should not become a system of counting and filling beds.

The quality assurance measures introduced by the government do not have the support of the community. It is our opinion that there are many other measures of quality assurance that get to the quality-of-life issues, and it would be much better to utilize these tools. We recommend that government work with the community to redevelop these tools so that they are in line with the perspective of the community.

I pass now to Michael.

Mr. Michael Kadey: Hi, I am Michael Kadey. I'm on the board of directors for Community Living Tillsonburg, and I'm also the vice-president of People First Tillsonburg.

Poverty issues: We have been trying to influence the social assistance review recommendations and poverty reduction strategies. We still struggle with our budgets, with the current levels of income support. We know that when we do have jobs, we have more income, but it's still pretty confusing. We have to submit what we earn each month and see our income supports go up and down, based on what we earn. We want to work more, but jobs are hard to find.

1330

We recommend moving to a quarterly report or like taxes, an annual report. We recommend higher amounts of earnings to be kept before clawbacks. Again, a private member's bill was proposed this last year.

We also contribute to our community in many ways. When we have the right supports to have a job and participate in our community, we help just like anyone else. We raise money for the Relay for Life. We volunteer in nursing homes, Meals on Wheels, child care centres. We help the BIA decorate our downtown, and we help keep it clean.

We do not believe that people should use their income support for paying for staff supports. We struggle with just having the basics on our incomes. We are active with the ODSP Action Coalition and have included a document of theirs in the package. We are generally concerned that people with disabilities have been seeing their benefits reduced.

Marty?

Mr. Marty Graf: I'm Marty Graf and I'm the chief executive officer for Community Living Tillsonburg.

Society does need to recognize the value of including people with disabilities in the workforce, and we have seen efforts to promote employment by both the federal and provincial governments. ODEN has also developed a Champions League of business leaders who promote the hiring of people with disabilities. We are proud members of ODEN and have provided you with some recommendations on employment. We recommend that Ontario consider an employment-first strategy, as explored at the recent ODEN conference. When the labour shortage hits, people with disabilities will be seen as one of the

solutions. We believe that people's lives are enriched when they are able to participate in the workforce.

With children's services: Families with children with special needs do best when they have access to the supports they require. We see the value of respite and have developed effective strategies with families. We develop funding from many sources to ensure that families get the breaks they need over the summer and during school breaks.

We're now into our third ministry for our children's services over the last 15 years. There is instability in the child care system as the full JK-SK system continues to unfold. As a government, you need to stabilize the remaining child care system. There is concern that as we shift into our third ministry, no one will know or understand what we do at the community level to help sustain families. Our children's services has provided you with recommendations on supports to children with special needs and their families.

On the application and assessment: These tools don't fit well with community beliefs and values. The tools need to be adjusted so they can fit with community beliefs and values. We know of people not willing to be put through such a process. They drop out and will require more services later.

In regard to housing: Many Community Living organizations have developed the capacity for property management through partner corporations. We provide a mix of housing options that include specialized housing and accessible housing. We ensure that the rental rates are affordable, and it is done under the not-for-profit model. We also see that landlords in general also seek out people we support as tenants, as they know they have a history of being good tenants. We also see the benefits when people have access to affordable, subsidized housing options in their community. We recommend the government work with us to expand the housing options required. We have worked with financial institutions over the years to develop our housing options, and they need to be included as part of the plan.

Supported decision-making: We recommend that Ontario take the lead in entrenching supported decision-making into the legal system in Ontario and Canada.

We've been trying to keep up with all that you are hearing from the community. You are hearing much wisdom and compassion and determination from the community. You need to unleash the talents of our sector so that we can solve these problems with you.

We thank you for the opportunity to present and look forward to your questions. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. We have about a minute for each party to ask a question, so if there are any, they should be very brief.

Mrs. Christine Elliott: Thank you very much for coming and making a presentation to the committee. You've raised a number of excellent points.

We don't have a lot of time, so I was wondering if you could expand a little bit on some of the innovative

housing solutions that you've been able to develop, because we've consistently heard that that is an urgent need, and that's why we're here: to hear about some of the prospective solutions.

Mr. Marty Graf: Years ago, we had a big residence where 20 people used to live together. We learned that people don't like to live in that kind of setting and with that many people, and over the years we've been able to transition out of those larger environments. Our agency took risks: "Let's pull together the down payment and start buying some housing," and we've been in that business for close to 30 years now. So you can have a triplex where somebody who requires a lot of supports is getting that. People on the second floor are getting the benefit of access to those supports, but they're not needing 24-hour supports. The person in that top-floor apartment just needs a checkup once a day or two times a week. They are accessing supports that are there 24 hours, but they don't require that. So we've changed from trying to have everybody in group-living situations to trying to figure out the best way to individualize. A lot of people can't live with four or five other people, and so they're better off when they can share access to supports, but not necessarily having 24-hour supports.

The Chair (Mrs. Laura Albanese): Any other questions? Ms. Taylor.

Miss Monique Taylor: Thank you for being here and for presenting to us today. You brought up something that I hadn't heard of before: It was called ODEN. Could you speak on that a little bit further? It's under "Employment."

Mr. Marty Graf: You'll see that they have developed some recommendations. It's a collective of us who have been around for years. Joe Dale is the executive director. We used to be big in developing sheltered workshops, and then we realized that employment is the best way to go. So there's a collection of us throughout Ontario. We have really focused on employment programs, and we strongly believe that is the best way for a lot of people to gain independence.

Miss Monique Taylor: So is it members by employers?

Mr. Marty Graf: We are connected to a lot of employers. They have developed this Champions League with us. It has the support of the Lieutenant Governor. But first and foremost, the members are the agencies who provide employment services for people with disabilities.

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Soo Wong: Because of time constraints, can you forward to the Clerk—one of your recommendations is about supported decision-making. So can you elaborate on that statement and share with the committee what you mean when you ask that Ontario take a lead in entrenching supported decision-making into the legal system in Ontario and in Canada? If you could submit something to us, that would be really helpful.

Mr. Marty Graf: Yes, we'll make sure to submit that to you.

Ms. Mitzie Hunter: I would also ask for your recommendation on the quality assurance model. You sug-

gested that there were best and good practices that you're familiar with, and I was wondering if you could share that with the Chair as well.

Mr. Marty Graf: Yes. There are a number of accreditation programs available that are possible options for agencies like ours. So I can get that information.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): We thank you very much for presenting before the committee today.

Mr. Marty Graf: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Continue the good work.

1340

MS. MARY JO WINKLER-CALLIGHEN

The Chair (Mrs. Laura Albanese): Our next presenter, Mary Jo Winkler-Callighen, is actually not here. She wasn't able to come and present to the committee. She has sent her presentation, though, and we have now Joyce Balaz, who will read it into the record. So just to be clear, we won't have any questions. The presentation will be read into the record on behalf of Mary Jo Winkler-Callighen.

You may begin.

Ms. Joyce Balaz: Thank you for your indulgence in this. She tried very hard to get volunteers. She's on a ventilator and she needs to travel with two people. She also could not get Paratransit to pick her up, and her technology also broke down, so all three strikes against her. I'm passing along a picture of her so that people know who she is.

"We have created a great divide. We put the temporarily able-bodied on one side and the rest of us on the other. All my life, I've been on the privileged side, the temporarily able-bodied. Very luckily for me, I met a man who, with extraordinary effort and against social norms and bypassing the structure of well-intentioned, supportive governmental programming, integrated into community across the great divide.

"I have the great good fortune to call him my friend. About four years after we met, I began to lose the use of my legs and feet, then my arms and hands, then my voice and neck, and now, some of my intellectual capacity. Without my good friend to show me the way, I could never have imagined remaining active in community. He opened my mind to possibilities that would have been closed to me by my own assumptions. He gave me hope; he taught me how to negotiate my way through relationships and through life. I would not have found this vital guidance without him.

"If he hadn't been integrated into community, our paths would never have crossed.

"When we bridge that great divide, we regain the wholeness of our humanity. When we are making full integration real, we begin to heal the rift, and mend the old and cruel great divide. We learn to value one another and accept our bodies and our minds. We cannot do this without full integration.

“I had much more to say, but my technology has failed me, and this kernel will have to say it all for me.

“Thank you.

“Mary Jo Winkler-Callighen.”

The Chair (Mrs. Laura Albanese): Thank you very much for reading that into the record, and give our best to Mary Jo.

SPECIAL SERVICES AT HOME/PASSPORT COALITION

The Chair (Mrs. Laura Albanese): We now have as our next presenters the Special Services at Home/Passport Coalition. Good afternoon and welcome to our committee. Just make yourself comfortable, and whenever you feel ready, we can start. Please identify yourself before you start your presentation so that we know who everyone is.

Ms. Susann Palmiere: Hello. My name is Sue Palmiere, and this is my colleague Janice Strickland and my daughter, Alexis Palmiere.

We’ve done four handouts. One is a brief, and I’ve done a point-form outline of it that you can just follow along with as I read it. Another one is a handout about one of our committee members’ sons, Dave, who had a full life with direct funding. And the other one is called Social Exclusion, which is a paper we did in response to some of the problems that have been coming up. We did that in June.

I’d like to introduce our coalition. The Special Services at Home/Passport Coalition is a volunteer group of families, individuals, organizations and agencies that are dedicated to ensuring that people with developmental disabilities and their families in Ontario receive the meaningful support they require through direct funding. Our coalition believes that all people have the right to self-determination, and therefore a right to choice and control over the supports that so affect their lives. We believe direct funding ensures supports that are flexible, responsive, individualized and self-directed and that result in relationships that are meaningful in community, and should be the support options of first choice.

I’d like to just go over a quick history of the Special Services at Home and Passport programs.

Direct funding was introduced by the government in 1982. It was introduced as a way to assist families and prevent the admission of children with developmental disabilities into provincial institutions. At the time, it was defined as a program of last resort, to be used when all other options of support had been exhausted. The program was immediately very successful with families, so much so that in 1987 there were many more applications than there was funding. In 1989, which is the year that our organization started, they expanded the program, in fact, to cover children with physical disabilities and adults with developmental disabilities.

If you see the chart on the point-form outline—I’ll just address that. In 1993, there were 9,000 families who were covered by a \$28-million budget. In that same year,

actually, the family groups, including ourselves, made recommendations to the government that program funding be doubled. We also made some other recommendations for improving the efficiency and effectiveness of the program, but I don’t know if they were adopted.

In 1995, the government increased the budget of SSAH by \$6 million. I should mention that the government always told families that they could apply for as much as \$10,000 annually per person. The average allocation for someone with SSAH is around \$4,200, and that has not changed. We’ll talk about that later.

In 2001, the budget increased to \$56 million and it served 16,900 families; in 2002, 18,500; in 2003, 17,200. The only point to note with this is that as the demand for the program increased, which it did, so did the wait-list.

In 2008, the ministry funded absolutely no new applications. However, they continued to encourage families to apply to the program so that they could gauge demand.

Then, in response to the growing wait-list—and you’ll see that by 2012 the wait-list is almost 9,600—in 2011 they put \$11 million into the program, which I believe funded 950 more families, but it only reduced the wait-list by 20%.

Finally, in April 2012, the government announced that SSAH would no longer be available for people over the age of 18. You’ll notice, in 2012, that the people served were 27,000 and the people waiting were 9,600.

Then, in April 2013, people over the age of 18 with developmental disabilities were cut off SSAH funding.

We’ll just go on to Passport. I’m hurrying; I want to get through this so we can answer questions. Passport is a very recent program. It was introduced in 2005 to assist young people with developmental disabilities who are transitioning from high school to community life by fostering skill development towards independence and autonomous decision-making. Funds were used for community participation, continuing education and personal growth.

You’ll notice the chart, and that’s page 3: In 2010, the budget for Passport was \$31 million; people served was 2,492; people on the wait-list, 3,959. In the next year, 2011, with the same budget, 2,700 people served; the wait-list was 4,500 people. So throughout the entire time that Passport has been in existence, the wait-list has exceeded the number of people served.

We have asked for recent statistics for 2012-13 from the ministry a couple of times and we haven’t received any.

As far as our last statistics, in 2012, there are now, to this day, 4,500 young people waiting for Passport funding and 9,600 families and children waiting to be funded through SSAH.

1350

This brings us to our next heading, which is that direct funding is a have-not program. You see our graphic; we call it our teeter-totter graphic. These are from information from the ministry. In March 2012, 9% of the developmental services budget went to SSAH and Passport; 91% went to everything else, from maintenance of the

system to supporting those individuals on government care and to building the bureaucracy needed to implement the new social inclusion act. Community Living Ontario estimates that as little as 15% of the new funding announced in the past seven years has gone to address the needs of people on wait-lists.

I really want to get to what the benefits of direct funding are. I did want to mention, however, transition. As you can see, there are problems in the developmental services sector today resulting from the years of underfunding—also now, from the manner in which the social inclusion act is being implemented: in effect, institutionalizing wait-lists and denying support to thousands of people.

One of the most urgent problems that has come out lately from the implementation of the act concerns transition of children from children's services to adult services, and how it coincides with a number of other difficult transitions. At 18, SSAH funding ends and families must take their young person—they apply to DSO, who do a SIS assessment. That's their very intensive and intrusive supports intensity scale assessment. Then they're placed on a wait-list.

If there's a significant time lag from losing their funding to getting new funding through Passport—which there usually is—or a significant difference in the amount, the person loses the support worker they've had for many years, as well as, at that time, losing the school community that they've known for many years as they transition from school to the community at 18 or 21.

Also, there is, at 18, a significant transition for our young people. Many of the people with developmental disabilities have associated psychiatric, medical and physical disabilities—and I know that you're looking also at dual diagnosis—and they are served as children within the children's hospitals or the children's treatment centres. Both of these institutions absolutely discharge at 18. So all of the services—OT, speech, physiotherapy, vision services, psychological services, and all the pediatric medical specialists—all access to those services ends, and the families have to find these services within the adult sector.

You've heard from H-CARDD, I believe, and Surrey Place. People with developmental disabilities are a very marginalized group in the medical community. There is very little expertise on, certainly, dual-diagnosis developmental disability, and there's very little expertise on the quite rare disabilities of childhood onset. They're usually rare, and it's very, very difficult to find service. The system is structured to precipitate crisis and family breakdown at transition.

It has often been said by families and ministry staff together that SSAH has been one of the most successful programs that the ministry has ever introduced. The reasons for it are fivefold.

Direct funding is cost-effective. I know you're familiar with the Drummond report. He observed that the recent legislation recognizes that people want life in the community, and they want choice and control over the kind of supports that allow them to live in the com-

munity, so he recommended moving towards consolidating developmental services funding for community-based support programs into a single direct-funding program. Certainly, what we as families can comment on with regard to that recommendation is that as families we are very, very skilled at obtaining value for very little funds.

Secondly, direct funding allows for flexibility in the use of funding to respond to specific situations and changing needs. I'm going to use personal examples on the next board, because I'm most familiar—keeping in mind that people with developmental disabilities are extremely varied in their needs and so we use direct funding in differing ways to meet those needs.

My children seemed fine, if a little bit unsteady on their feet, at one and three, but they were diagnosed with a progressive neurological and immune system disorder that involved progressive loss of the cerebellum, which is the back portion of the brain. The cerebellum controls all motor movement. It controls fine and gross motor movement, coordination, balance, vision, speech, swallowing and digestion. The cerebellum also has inputs into cognitive processes; in particular, information processing.

Very quickly, we were seeing all sorts of specialists, and then therapists in the children's treatment centres, with various therapies and what have you at home. I was pretty well required to leave work to meet all these needs, and that entailed my husband taking on more work travel and in fact work outside the country in order to compensate for the lost income. So I was alone, and we were trying to meet all of these needs.

Now, home care was available in our area. It was VON and Red Cross, but the workers in a rural area were often unavailable. They were constantly changing. They couldn't do the therapies and procedures we needed them to do. They couldn't come with us to appointments—that was a biggie. But the biggest thing was that they weren't trained in the care of children. They were trained in the care of the elderly.

I really feel that, for children with a progressive disability, building emotional resilience is of utmost importance. Building a sense of competence and agency and a sense of self in the presence of this is vital, but to do that, you need to know something about child development. So the SSAH coordinator found a young woman from the University of Guelph studying family studies, and she knew quite a bit about child development. She was able to grasp quite quickly values around disability and empowerment, and she was with us for five years. I'm just using this as an example of how SSAH can respond quickly to the needs of a family, whereas the Ministry of Health was unresponsive, inflexible and very expensive.

The other thing about direct funding is that it does encourage creativity and the use of available resources to achieve desired outcomes. By the time my son—my son also has this same disability—was nine, he was beginning to lose the ability to walk and was resisting going into a power wheelchair. Now, at school, the boys would be out on the field playing, or they'd be riding bikes after school. As a result, he wasn't able to keep up, and he was

losing his friends. He responded by withdrawing into about two video games. It's all he would do, these two video games, and we were getting really concerned about his behaviour.

So we hired a young man—again, a student from Guelph, a poli-sci student—who would come every day after school, sit on the floor and play these two video games. He did this for weeks, but gradually he persuaded Sam to try some more challenging video games. Following that, then, was Ryan's favourite activity, canoeing. This was followed by disabled sailing, then disabled skiing, then power wheelchair hockey. And so, with time, Sam became pretty proficient in his chair and a good goalie, and started defining himself as a sports guy in a chair.

Eventually, after six years, Ryan left. He was replaced by Curtis, another student. He was a YMCA day camp counsellor, so Sam became a summer day camp counsellor volunteer.

By the time Sam got into his early twenties, he finally admitted to Curtis that he really hated disabled skiing and he wanted to scuba dive. He and Curtis found a program out of Ottawa that teaches people with disabilities to scuba dive and snorkel, and he's been an avid participant ever since.

We all discover who we are by trying new things and meeting new people. Direct funding allows people with developmental disabilities to do this as well. Direct funding also helps people achieve personal growth and realize self-determination.

When Alexis was eight, we took her to an educational psychologist, and he more or less said, "Well, her scores are really low but it's difficult to test her because she's visually impaired and the physical disabilities, but she has a remarkable memory, and you just build on that strength and forget all the rest of it."

1400

In fact, her EAs at school more or less gave up on the technology anyway. They just read to her all the way through her school. As a result of this, she developed just an incredible auditory memory.

At 21, Alexis graduated with a diploma, supported and accommodated. She wanted to go to college with her classmates. After a few false starts, we found a college without entrance exams and they said she could take a course. Then we found April. April was as fiercely dedicated to Alexis and her abilities as Alexis was dedicated to education. She spent months training Alexis in an on-screen keyboard, use of a joystick, word-predictive software, reading software. Alexis took the course, but she found it agonizingly difficult, and she didn't do terribly well and she hated it and she was crushed because she had dreamed of being a teacher of young children, like her grandmother.

With nothing else to lose, we said, "You should really do what you're interested in," so we went back to the college and talked to the early childhood education program. They allowed her into a course. She took the one course, loved it, and she has been doing them ever since. The material that she reads and memorizes gives

great meaning to her volunteer work in daycares and also greater depth to her relationships with the children of caregivers. So I say that direct funding has helped her realize some of her dreams.

Finally, direct funding helps build informal networks of support in the community. All of us are part of a network of relationships through work and school and recreation and community involvement, and they give us identity and belonging and some fun and they give us assistance. This, of course, is our informal network of support. People with developmental disabilities have very fragile informal networks of support. They have formal networks of support that are changeable and often compromised. What has to be done for people with disabilities is, they need informal networks of friendships and support built intentionally.

Sam and Alexis, as you can tell, have had a lot of really terrific workers, who all move on. They come as students and they move on to adult life. They go on to graduate school and professions and marriages, but many of them have wanted to stay involved. It's difficult for Sam and Alexis to sustain relationships. What we've done is we have formalized their engagement with the kids' lives by starting planning circles. The circles help with decision-making—you don't want your parents helping you with decisions all your life—and problem-solving around school, work and recreation. They provide social opportunities. Each circle is eight members. They meet every six weeks, and they've been meeting now for seven years. It's funny, but the workers now come back with all the skills they've gained in their professions. One guy has a master's in education. He's a fabulous group facilitator. Another girl, because of the kids, became an autism specialist and so she's very good in educational accommodations.

The Chair (Mrs. Laura Albanese): Sorry, I have to let you know your time is up. We've actually exceeded the 20 minutes.

Ms. Susann Palmiere: Can I say one more thing?

The Chair (Mrs. Laura Albanese): Yes, please.

Ms. Susann Palmiere: It's to do with family mentoring, and perhaps you can read the brief there. Families are central to the lives of people with developmental disabilities and are key, actually, to making the system work. I made a couple of points as to how what's going on right now has really made families unable to continue helping their family members achieve a meaningful life in the community. Perhaps you could read that.

Do we have any time for questions?

The Chair (Mrs. Laura Albanese): No. It has been exceeded; I'm sorry. But it's important that we hear from you, so we thank you so much for the presentation and for being here with us today.

Ms. Susann Palmiere: Thank you.

MS. JOYCE BALAZ

The Chair (Mrs. Laura Albanese): We'll now call Joyce Balaz back for her own presentation this time. Joyce is accompanied by two people.

Ms. Joyce Balaz: Sorry for the time delay. I'm Joyce Balaz. I'm from London. I'm accompanied by Bill Hiltz and his intervenor, Arn.

With the indulgence of the committee, I would like to ask you a few questions—turn things around a little. Do you have friends who are not paid to be with you? Were those friendships developed through your interaction in the community, be it your workplace, your place of worship, from the time you were in school, maybe a service club? If you are in a relationship with a significant other, how did you meet that person? I'm sure that it didn't happen when you were out in the community with your mother, right? How many people would you like to have provide very intimate care for you? Are you able to choose the group of people you spend a lot of time with? Do you think that your role in society is a valued one? I ask these questions to provide you with an opportunity to understand a little bit better why an individualized approach that allows for choice is so important.

Because you've chosen to sit on this committee, I believe you feel that the current system is quite badly broken, and I believe that what you've heard thus far supports that notion. I believe that the root of the problem is that the system is built and continues to be built to support the system and not the individual.

When I say "individual," I mean an individual living with a developmental disability. When I say "family," that includes family, friends and advocates.

I am a family home provider for this gentleman, Bill Hiltz. To most eyes, Bill is a broken-down individual who is most often pitied, but certainly for the most part, he is not valued for the contribution to society that he has made.

While Bill is not the usual candidate for a family home placement, I can tell you unequivocally that this is the best place for Bill. Having been his educational assistant, I knew that Bill had many gifts to share. Because of the relationship Bill and I had developed, when he needed a new home, I offered to have him come and live with me. It was then, in 1996, that I became his family home provider.

After Bill left the education system in 1998, once again he fell through the cracks in between systems, and his intervention needs were not met. It took us six long, hard years of advocacy to obtain these supports. During this hard advocacy, I was effectively silenced and Bill's rights as a citizen were trampled upon. It took the support of many individuals for us to maintain the strength and advocacy to ensure that Bill's rights were upheld. I cannot begin to explain to you the enormous stress that we endured. I wish I had time to explain all of these things more fully, but there are more important things to discuss with you.

I paused here to illustrate what many individuals who have lost or have no supports are subject to for many hours in the day: They can do nothing.

1410

Bill and I are very active politically because we feel that if one wishes to complain about a situation, one must

be ready to roll up one's sleeves and bring about change. That is what brings us here today.

We are involved in many organizations that advocate for individualized supports. We have experienced the benefits of independent facilitation, without which Bill and I would no longer be together. We have lived through the harsh intimidation of the powers wielded by the system, but with the strength of Bill's support circle and the support of the facilitator, we survived an ordeal I hope no one else ever has to endure.

I only mention this because it is important for you to understand that power can destroy wonderful relationships and truly harm individuals and families. But on a positive note, seeing a vulnerable individual become empowered through the support of others is so inspiring.

Bill's accomplishments are many, far more than those of many of us in the room put together. He inspires me to higher heights. He is an inspiration to many. We have distributed posters of Bill's accomplishments as well as a snippet of his community participation.

All of this would not be possible if Bill's supporting agency did not believe in individualized supports, and it would not be possible if I did not provide the level of care and support that I do for Bill.

I said that we are here to bring about change. It is time that MCSS recognizes and values the unpaid supports of the many people who provide support day in and day out. Over the past 18 years, I have done the math, and I have saved the ministry over \$1 million by providing 16 hours a day of support and then some. The ministry refuses to acknowledge the savings because they believe it is not a savings, because they didn't have to pay it out first. I receive a per diem of \$47, from which I must also provide for Bill's housing and meals and anything else he needs. I have not had an increase in that per diem in four years.

The most probable placement for Bill, if he were not living with me, would be a group home for individuals who are deaf-blind. I did a cost analysis about 10 years ago, and at that time, Bill's supports would have been at least \$150,000 a year. I am quite certain that the amount is probably higher today, and those supports would not provide for the one-on-one support that Bill requires.

I must point out here that for a significantly lower cost, Bill has a much better quality of life, individualized to his needs, and one that acknowledges his gifts and talents.

I also want to point out that, contrary to the beliefs of CUPE and OPSEU, the same level of support is possible through an individualized approach. However, there is an inherent danger, and that is that historically, individualized supports remain stagnant, and therefore people begin to fall behind those individuals supported through a transfer payment agency.

I also wish to point out that there has been no increase to Bill's intervention funding since it was secured in 2002. This presents a challenge because in order to retain good workers, we have to pay the same rate as people working in agencies or else we lose those workers to the

agency positions, which provide benefits and job security.

One important change we see for individuals is to immediately implement an entitlement to independent facilitation and planning prior to the assessment process so that individuals who require supports to lead an everyday, ordinary life can, at the very least, have an opportunity to dream and experience the value of developing relationships within community. With this experience, individuals will be better able to identify what supports and services they need in order to be a valued, contributing member in their community.

The second important change is to develop a method so that dollars that are allocated for CCAC care be individualized so individuals can add those dollars to other funding to allow for supports which better meet the needs of the individual. I provide more details about this in my written submission.

By allowing funding to be combined, we could hire another full-time intervenor, giving Bill more direct support. Bill would then be able to choose which worker would provide the best supports for each activity he's involved in. Not only would this provide for optimum supports for Bill; it would also provide more dignity, as there would not have to be six people providing intimate care for Bill in a week. As in the MasterCard commercial, this is priceless.

Another very important change that would make things much better for everyone is to work across the various ministries to develop a registry for individuals with developmental disabilities. Since developmental disabilities usually emerge at an early age, there should be no need to reapply for services and supports at age 18. If a child is entered into the registry upon diagnosis, it would be easier to plan for the future and to provide numbers with which to advocate for more funding.

The transformation process is moving too slowly. It began in 2004, and people were hopeful. Now, 10 years later, things have gotten worse for a lot of people. People have lost hope and trust in the process. Part of the problem is that the transformation is based on bad legislation. Once the legislation was crafted and passed through debate to the final committee process, many advocates were absolutely disgusted by the process. Even sound transformative amendments were shoved aside and not considered because they originated with the opposition. This highlights that the process served only the government and not the people that this legislation is intended to serve.

Currently, the DSO process, which was developed to be a single access point for service, is an unwieldy process. It is not responsive to individuals and their families. It is another bureaucratic layer that has taken in excess of \$12 million away from the direct support of individuals. It does not allow for the immediate call to action in times of crisis. Alternately, the application process should be as easy as applying for an accessible parking permit or the disability tax credit, which can be completed by the family physician. It would not be difficult to develop a

simple questionnaire to determine whether there is a developmental disability. Once the simplified application form is completed, an individual and/or family could present the form to a ServiceOntario office—which is already an existing entity—and provide proof of residency in Ontario and then proof of age. The personnel would accept the application, electronically add the individual to a registry and things could proceed from there.

Provide a six-month deadline for everyone currently receiving supports through ACSD, Special Services at Home, Developmental Services, ADP and wherever other people get some services from, to apply as explained above. As well, put out a call through family networks, various community organizations, ODSP and OW offices, subsidized housing, CCACs etc. to connect with those individuals who haven't bothered to apply because they know there are no resources available. In this way, the government would have the required data of a number of people who currently require supports and services. While this would not have the information on the level of support that the individuals need, it begins the process.

From there, everyone who is deemed eligible through this process must be entitled to independent facilitation and planning to begin the dream of what life looks like for each person. At least everyone gets a start. This independent facilitation and planning must take place before individuals enter into the assessment stage to determine the supports they need. The facilitator can also help them navigate through the system.

Independent facilitation saved our life together; without it, Bill would no longer be living with me and, in the opinion of his neurologist, he would not be alive today. I can tell you, that would be a real crime. Bill inspires so many people. To illustrate how important change is to Bill, he has opted to not use his energy to enjoy his life but has instead decided that he will only work on his advocacy role to help those who have no supports, to help others understand that they have a voice and that they can do whatever it is they want. His words to fellow classmates when he left school were, "Great things are there for you if you choose to work for them."

Investment in community development is needed to help break down the enormous attitudinal barriers for people living with disability. An example of some basic community development that would reduce the financial burden on the ministry is to ensure that all parks and recreation staff are fully trained in assisting people with developmental disabilities who require minimal support. There is always apprehension when people first begin to interact with individuals. But, over time, when it is commonplace for people to be active in the community, that apprehension melts away and makes room for some very honest relationships.

I witnessed this with Bill in the environmental studies class one year. The mix of students in the class was such that after Bill and I had joined the class for their yearly Cyprus Lake camping trip, once back at school, Bill

would lead me out to their class and the students included him in whatever they were doing as if it was commonplace. At other times, if we came across one student in particular at the cafeteria, Bill would choose to spend time with the group of students that she was with at the time. I left Bill in their care and backed off with my support. It turns out that the summer after that, Bill hired one of those students to be his intervenor for the summer. This was a wonderful example of building relationships in society. This is true inclusion.

1420

Another issue which needs to be addressed immediately is one of inequity. The program being a discretionary one breeds inequity. "Discretionary," by definition, identifies choice, but whose choice? Funding is allocated at the whim of the government, and unfortunately, our most vulnerable population is not seen as a priority. For about 25 years, advocates for individualized supports have been asking, through many forums, avenues and meetings with the ministry, to allocate 25% of any new monies added to the developmental services budget to be put towards individualized supports. A quarter of a century later, 10 years into the transformation process, and the ministry, despite its vision of social inclusion, has seen fit to allocate only 9% of the budget for individualized supports. There is a huge inequity here.

Despite the large proportion of funding being held by the transfer payment agencies, wait-lists for day programs and residential supports continue to grow. Bill has been sitting on a waiting list for a group home placement for at least 20 years. I keep him on that list because I do not know what will happen to him when I can no longer provide supports. We came very close to that point last year when I lost a lot of my mobility due to a deteriorating hip caused by osteoarthritis. Luckily, I was able to continue to provide support for Bill. It was rough after my hip surgery, but we managed—not without struggle and stress, but we managed.

In the statements already presented by others, including CUPE, OPSEU and various service agencies, you are hearing that the chronic underfunding is eroding their ability to provide the services that individuals need, yet they are quick to point fingers at the individualized supports as not being able to maintain supports and eroding the services sector. If the system moves to personalized budgets, there is no need to develop separate programs, as individuals will find what works best for them. For this reason, it is important that, moving forward, all budgets of people in service be personalized.

We acknowledge the fact that not all individuals want to strike out on their own with individualized supports. However, if budgets are personalized and fully portable and individuals find that they are successful in the community, they can move to individualized supports, and, depending on the other supports that they require, perhaps more direct service dollars can be found to better support the individual with community participation and community capacity building.

Another very important issue which we have not yet touched upon is the re-institutionalization of individuals

whose needs cannot be met with the maximum level of support in the community. Young people, because there are no alternatives, are being placed in long-term-care facilities. Ask yourselves this: Would you want to be living in a long-term-care facility at the age of 24? By keeping the system woefully underfunded, people are being forced back into institutions—this upon the heels of a very impassioned public apology to the residents of the Huronia Regional Centre on December 9. In that apology, the Premier told Ontarians, "Today, we strive to support people with developmental disabilities so that they can live as independently as possible and be more fully included in all aspects of their community. As a society, we seek to learn from the mistakes of the past, and that process continues."

The reality is that today we ship people off to nursing homes, mental health units, treatment centres and jail, depending upon the circumstances. Where are the community supports that were to be reinvested in the community when the Huronia Regional Centre, Rideau Regional Centre and Southwestern Regional Centre were closed? No one seems to know where that money went.

This brings us to a major problem with trust. The ministry is all too happy to trust families to care for their sons and daughters without providing any supports and services, but that trust really disappears when funding is attached to the support.

But what about the trust that people placed in the ministry? During the early stages of transformation, people were worried that individuals would lose their current level of funding. We were assured time and time again that this was not the intention of the transformation. Then what happens on April 1, 2013? Anyone who turns 18 loses the funding that they were receiving through SSAH because it has been converted solely to children's programs so that they can address the children's wait-list.

In the MCSS presentation you were told that there were no cutbacks. What is it called when funding is taken away under the guise of having to reapply to the adult sector to retrieve this funding? Individuals who had funding lost it, because there was no seamless transition between the child and adult service delivery.

Another issue of trust rose up early last week. We received a disturbing communication about a recent ministry publication entitled *Hiring a Support Worker*. The first statement is, "Are you a person with a developmental disability in Ontario? Do you get money from a job, a direct funding program, the Ontario Disability Support Program (ODSP) or another source? Would you like to use some of that money to hire someone to support you and your life in the community? Are you a friend or family member of someone who wants to hire their own worker?"

People have been identifying to advocacy organizations that the DSO, and even staff at the Ombudsman's office, are suggesting that if individuals do not have funding to pay for supports for community participation, they should use their ODSP income support to do so.

With the woefully inadequate ODSP, which is meant to provide for housing and food with a small pittance for other personal items, how can they even look to using this support to pay a wage to someone else? Not only is this unreasonable, it is probably illegal.

Individuals are being counselled to use one social assistance benefit to pay for something that it's not really meant to be used for. This is outrageous, as these are two totally different support programs.

When questioned about this, David Carter-Whitney told representatives at the partnership table that his earlier comments had been misunderstood, and that was never the intent, yet people are being counselled to do so, and now it is even written in a ministry document. How is anyone to trust anything that they are being told?

In summary, my recommendations to enable individuals to fully participate in their community and bring about substantive change to developmental services are:

- invest in community development as a way to move from a model of providing charitable supports to one that supports economic growth;

- move from a discretionary support program to one of entitlement, as our most vulnerable citizens have the right to participate in the community of their choice;

- ensure that individuals deemed eligible for supports and services are entitled to independent facilitation and planning;

- move to a system that supports the individual and not the system;

- implement personalized budgets;

- ensure that supports are whole-life based;

- develop effective inter-ministerial coordination to allow blending of budgets to provide for more meaningful supports for individuals; and

- last, but by no means least, it is time that people really listen to the individual. All they want is an everyday ordinary life, like everybody else. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your very thorough presentation. I believe that Bill now follows.

Ms. Joyce Balaz: Yes.

The Chair (Mrs. Laura Albanese): We don't have any time for questions for this first one.

MR. BILL HILTZ

Ms. Joyce Balaz: Bill has had some seizures this morning and this afternoon, so bear with us. We'll try to get him to do what he's supposed to do.

Mr. Bill Hiltz: Good afternoon. My name is Bill Hiltz. I do not speak with voice. I use facilitated communication, which takes a lot of time and effort, so my intervenor, Arn, will speak for me.

The Chair (Mrs. Laura Albanese): It automatically turns on as you start speaking. We have our attentive team here.

Mr. Arn Row: This is Bill's poem. It is called Understanding People.

A set of standards by which to judge,
to their friends, they give a nudge.

When they see me come their way,

they stop and walk the other way,

Or even worse, they stop and stare

as if I'm stupid and unaware.

If only they could know that I care;

how people view me—it's just not fair!

I feel the very same as others do,

they should try and walk in my shoe.

Life's not easy, when the body that you own

was given to you broken-down.

They may be mean; they may be cruel; they may be

bad;

but most of all ... they just don't understand.

1430

With some time and special guidance,

we can have a great alliance.

For an hour or for a day,

we all need friends along the way.

So when you see me come along,

try not to focus on what is wrong.

I am a person just like you,

who needs and deserves a good friend too.

Just walk beside me straight and tall

and be the friend that I can call

when I am lonely and afraid.

Just remember what I've said:

All you need is to understand;

do not judge, just take my hand.

I ask you now to open the bags that you were given and put on the items that are in there, just so you can get the experience of what it's like to live in Bill's world.

Ms. Joyce Balaz: Bill has graciously offered to give someone else his wheelchair for a time.

Mr. Arn Row: While Bill was working on this presentation, he was plagued by seizure activity as frequently as every two minutes. Despite this, he pressed on. The text in italics are Bill's actual words using facilitated communication. Anything not in italics was developed with Bill presenting the main idea, and then together with Joyce's skilled intervention, Bill was able to provide more detail and has approved if not the actual words, at least the content of the statement:

"I am not a client; I am a person first and foremost. I am a person who faces many challenges. I was not miraculously cured at age 18. My needs have not lessened. My seizures are getting worse as I get older, so I need more support to keep me safe.

"Does an expert need to tell you that I need 24-hour care, seven days a week? For many people like me, an expert opinion is not necessary; it is quite evident. So why the added expense for an expert opinion? Is it really necessary to spend scarce dollars unnecessarily on a full SIS assessment, when a simple questionnaire could easily determine the level of supports I need?

"It is important that families have the support to allow their sons or daughters to grow and truly blossom. That

support was not there for me and my family. I spent a lot of time in hospitals and foster homes. At one and a half, I became a crown ward and spent time in various foster homes before being sent to the Christopher Robin Home in Ajax. I spent a number of years there until I was rescued by a wonderful foster family when I was 8. I lost a lot of my childhood there.

"It was important for me to support the survivors of Huronia Regional Centre because they lost so much too. It is important for everyone to have a life in the community. It is very important to me to be able to continue my advocacy work to help others have the same opportunity as I do.

"These five guiding principles, which I helped develop with other board members of Family Alliance Ontario, will help everyone to have an everyday, ordinary life.

"An everyday, ordinary life: Having a developmental disability does not diminish the right to a life like anyone else in the community; it just means that people need varying levels of support to achieve many of the things that happen naturally for those who do not have a disability. By having an everyday, ordinary life in the community, people will be better able to develop the relationships that are an integral part of society.

"Whole-life-based supports: Supports must enable people to live a full life in the community from birth to the end of life. Individuals must be seen as a person, not as a sum of the parts of life: health, housing, recreation, transportation, education etc. Supports must be flexible to provide assistance as necessary through the various transition times in life because necessary supports at these different times in life are varied according to the challenges which emerge. Therefore, having the ability to draw from a whole-life-based budget for supports will allow for that flexibility to provide the supports necessary at any given time.

"Independent planning and facilitation: They are integral supports necessary to fully integrate individuals into their community based on their strengths and abilities. Planning must be more deliberate for people with disabilities, and facilitation provides for the relationship-building and the building of capacity in the community to allow for positive inclusion and a more caring community. Every individual deemed eligible for supports and services through development services must be entitled to independent planning and facilitation before starting the assessment process.

"Economic growth: Providing supports for a person with disabilities must no longer be seen as a charity. By providing adequate supports, individuals are providing employment opportunities for support workers. Family members who would otherwise be forced to stay home to provide supports to individuals are able to participate in the workforce, bringing more financial stability to the family unit. Individuals who become employed contribute to the economy. Individuals who become part of the volunteer network contribute to the community and to the humanity of that community. Families of individuals who are full participating members of society are faced

with less stressful situations and therefore enjoy a healthier life, reducing the cost on the health care system.

"Inter-ministerial co-operation: Developmental disabilities do not start when a person reaches adulthood, yet currently, the developmental services system only serves people 18 years of age and older. Developmental disabilities are generally recognized before the age of 2. Supports and services must be ongoing from the time of diagnosis to the end of life; therefore, there must be inter-ministerial co-operation to provide for seamless services and supports. It is ludicrous for people to lose services and supports when they turn 18 simply because it falls to another ministry. Disability affects all aspects of one's life, and as such, supports and services must be available to assist with life.

"It is time to stop studying what it is that people need and to start providing the supports and services necessary to enable a full life in the community, no matter what those may be, whether it be personal care, health care, physical and/or occupational therapy, housing, employment, mental health supports, community participation supports, transportation, issues with regard to the justice system and the legal system etc.

"The simulation was an important part of my presentation. It was my hope that you would better understand my life and why I need someone to help me with all parts of my life. I must trust those who help me to keep me healthy and safe. That is why it is really important that I choose those who support me. Choice in life is very important. Everyone must have the same opportunity to be a part of their community. Please make sure no one is left behind.

"If you have any questions, please ask the member sitting near you to read out what you silently say using the communication board supplied to you for at least one question. Thank you."

The Chair (Mrs. Laura Albanese): Thank you for providing us an insight into Bill's life.

We have two and a half minutes each, and it starts with the NDP, so Miss Taylor or maybe Ms. DiNovo.

Ms. Cheri DiNovo: Joyce and Bill, thank you so much for your presentations. Joyce, thank you for your advocacy; that goes beyond this committee, and we probably all had experience with that advocacy over the months and years.

1440

Just a question: I think we've heard from a number of families about individualized funding and individualized plans, and that the system is broken. I'm starting from there. My question, I guess, is for those families. Bill and Joyce, you're very lucky people to have each other. You're very lucky, all of you, to exist as a family.

There are, of course, those that aren't as lucky. They don't have family, so we are always going to need places for those folks too. I just wonder if you could speak a little bit about that, because that segues into some of the other presentations from Community Living about the cuts to funding for beds etc., so if you could talk about that.

Ms. Joyce Balaz: Absolutely. One of the things that we do like to let people know is that only about 30% of the population wants to have individualized funding, so we will never destabilize the system. The system still needs to be there. All we're asking is if the payment transfer agencies that are not as progressive as some of the ones that do provide the individualized funding and supports could see their way to making some changes so that there are not so many congregate living situations. I'm sure that, if you take a look, a lot of the people who are living in group homes were never asked if those are the people they want to live with.

The Chair (Mrs. Laura Albanese): Is it Ms. Hunter or Ms. Wong? Okay. Ms. Wong.

Interjections.

The Chair (Mrs. Laura Albanese): Oh, okay. I'm trying to understand which one is going to speak.

Ms. Soo Wong: She's pointing and I'm trying to speak. "Hello. I love—a great presentation. We need help to try to make the system better. Thank you."

Ms. Joyce Balaz: That just gives you an example of how difficult it is to communicate in a different way. Thank you for being brave to do that.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones, do you have any comments?

Ms. Sylvia Jones: Yes. Thank you, Bill, Joyce and Arn. My question is actually more of a comment about the challenges that we are now seeing in the system as a result of Bill 77 and that transformation, because some of us were involved in that process.

I'm pleased that you talked about the need for the individualized planning. I think that that's a step that would have helped a lot of families and a lot of individuals. We missed an opportunity there, but maybe we'll get it right this time.

You mentioned that only about 30% of individuals are looking for individualized funding. Do you find, in your experience as an advocate, that that relates more to the stage in life—that we all experience different needs, desires and motivations as we go through—or is it just that 30% is the average?

Ms. Joyce Balaz: I don't think it really depends on age, demographics or stage of life. I think it depends on the advocacy of the family. I think it really depends on what kind of supports the individual has. If there is a support circle in place, those people are probably more likely to want to have individualized funding, because they have supports behind them. Does that help?

Ms. Sylvia Jones: Yes, absolutely. It's the opportunity, essentially.

Ms. Joyce Balaz: Right.

The Chair (Mrs. Laura Albanese): That makes sense. Thank you.

Thank you very much, not only for being here and for presenting to us but for giving us the opportunity to really have an insight, as I said before, into what Bill's life is like, and for all the work that you're doing. We'll do our best to get it right.

Ms. Joyce Balaz: Thank you, and thank you for all being so brave to sit through that piece, because it's not easy. Thank you.

The Chair (Mrs. Laura Albanese): Yes?

Mrs. Christine Elliott: If I might, while we're waiting for the next presenter to come forward—

Ms. Joyce Balaz: Can I just mention that one of Bill's accomplishments is that he was an Olympic torch bearer? Should anybody wish to hold the torch after, one of the things he likes to do is share that with people.

The Chair (Mrs. Laura Albanese): Excellent. Thank you.

Mrs. Christine Elliott: Madam Chair, one of the issues that came up in Ms. Balaz's presentation was the communication about hiring a support worker that came from the ministry. I'm wondering if we could ask research to get a copy of that pamphlet or presentation and also to get clarification from the ministry with respect to the intention behind it.

The Chair (Mrs. Laura Albanese): That's very good. Yes, we will ask for that.

CROSSING ALL BRIDGES LEARNING CENTRE

The Chair (Mrs. Laura Albanese): We'll now ask the Crossing All Bridges Learning Centre to come forward. Good afternoon, and welcome.

Ms. Debbie Brown: Thank you for having us.

The Chair (Mrs. Laura Albanese): You may start at any time. Please state your name and your title before you begin your presentation so that we can record those in our Hansard proceedings.

I believe you know you have up to 20 minutes for your presentation. Should it be shorter, we'll try to divide the time if there are any questions.

Ms. Debbie Brown: Thank you. My name is Debbie Brown. I'm executive director of Crossing All Bridges Learning Centre. I am one of the founding mothers of Crossing All Bridges. I have a daughter who is autistic, and she's 32 years old.

Ms. Nancy Gowing: I'm Nancy Gowing. I'm the board treasurer. I'm one of the founding mothers also. I have a son, Scott, who is 31 years old, and he has Down syndrome.

Crossing All Bridges Learning Centre would like to take this opportunity to thank the select committee for taking a major role in trying to improve the quality of life for people living with a developmental challenge.

Crossing All Bridges was founded by four mothers, two of which you see today, who were very concerned about the future of their adult sons and daughters, who were getting ready to graduate from the high school system. That was 11 years ago.

In looking at the options available at the time, it was discovered that there were few choices and opportunities in our community to provide purpose and meaning to their day. We believed that our developmentally chal-

lenged adults should have the same options as our other sons and daughters.

In our search to fill a gap in opportunities, we looked to what made our sons and daughters happy and what they felt was important for their life plan. They believed that keeping friendships with their peers is very important. They wanted to continue to learn so they could contribute to their community, and they wanted opportunities to be available to them. Crossing All Bridges opened in 2003 to fill these needs.

We are a not-for-profit registered charity that operates on a tuition basis. Tuition fees represent 54% of our revenue. The rest is raised by funds from grants, fundraising and donations. Crossing All Bridges does not directly receive government funding, but we have searched out partnerships with the federal programs—the jobs creation program and Canada Summer Jobs—and Employment Ontario.

We currently service 52 people with developmental challenges, of which many have dual issues. The age range of our students is 18 to 58 years of age. Over our 11 years, we have serviced almost 100 individuals. We have a staff of seven full-time employees, connections with Mohawk College, Wilfrid Laurier University, Medix school and local high schools where we provide co-op student placements. Crossing All Bridges has several volunteers who contribute approximately 3,000 hours yearly.

1450

Our students come from a service radius of 60 kilometres. Our mission: provide dynamic programs and opportunities to maximize the individual potential of adults with intellectual challenges. Our daily offered programs continue to evolve to meet the needs of the students. In the beginning, we were perceived to be a post-secondary option for students leaving high school. Many of Crossing All Bridges students watched their brothers and sisters go off to college or university, so they wanted the same option.

To date, Crossing All Bridges Learning Centre has been a model for several other communities in the province of Ontario. We have had North Bay, Kingston, Windsor, Guelph, Hamilton and Amherstburg visit our site. Three of these now offer similar programs in their communities. Recently, we had staff members from Yarmouth Life Skills for Disabled Adults from Nova Scotia come and visit our model.

Ms. Debbie Brown: We are at a stage in our development where many of our students have been with us since we opened our doors. Crossing All Bridges is investigating and developing social enterprise as a viable employment option for adults with intellectual disabilities. In our 11 years of experience, only 7% who participate in our day programming have been able to successfully transition into and maintain part-time employment at local businesses, using a variety of the supports currently available in our region. CAB would like to see that number increase.

This is where social enterprise comes in. Social enterprise is simply a newly branded term for the ways in

which non-profits and charitable organizations have been making money through business ventures. As a business model, social enterprises often have a dual or triple purpose that involves generating income, delivering an organization's mission or meeting social and/or environmental aims. CAB is primarily interested in considering social enterprise as a model that would generate stable employment and income for the individuals with disabilities who face barriers in attaining and maintaining employment.

In a perfect world, there would be no need for social enterprise. However, the statistics that CAB has gathered suggest that some individuals are not able to transition into mainstream employment. Social enterprise provides another option for individuals who are not able to successfully transition into mainstream employment with non-disabled individuals.

This initiative strengthens CAB's organizational capacity and encourages it to further meet its mission to provide continual, meaningful opportunities for individuals with intellectual disabilities. Currently, CAB is servicing individuals between the ages of 18 and 58 because there are few opportunities provided for adults living with intellectual disabilities. Social enterprise would provide another avenue of choice, enabling these individuals to meet their life goals. CAB requests that support be made available for social enterprise as a distinct option for employment supports, especially to start-ups beyond the major urban centres in this province. With the government's acknowledgement and support of social enterprise, CAB and other organizations across the province can help more adults to succeed in employment.

Crossing All Bridges Learning Centre recently hired a full-time person to research social enterprise to begin the process to address the employment needs for the people faced with developmental challenges who live in the Brantford and surrounding areas. We are currently writing grants for funding to support the feasibility study, followed by a business plan and move into start-up for two social enterprises.

Employment can be exciting for young people just leaving the high school system, especially so for those who have had training or co-op experience while attending high school. It appears that some special education students have had success with co-op programs while many in the segregated special education classrooms have not had employment options. Special education students who have not had any training or co-operative employment opportunities would benefit from the ODSP Employment Supports program, but families are not educated or informed of the services offered by the Ontario government. More communication and knowledge is needed to further this option. High school transitional plans should be inclusive of all options for students and their families.

The government of Ontario could play a more active role in the social enterprise opportunities for people with developmental challenges. Pots of funding should be available for calls of proposals.

Crossing All Bridges made recent calls around the Brantford area to inquire about employment training opportunities for adults with developmental disabilities. We found very little that pertains specifically for adults with developmental challenges. We are here today to discuss our model and the positive impact we have had for the people we service and their families, along with the risks that face us going forward. We are here to talk about the future for adults with developmental challenges who have completed their secondary education and now live within the community.

Ms. Nancy Gowing: Here are some of the challenges that we are currently facing.

Tuition fees: Crossing All Bridges operates on a fee for service. The students of Crossing All Bridges have been utilizing their Passport funding, formerly known as Special Services at Home, as a means to meet the tuition costs. Since the conception of Crossing All Bridges, the organization has endeavoured to keep the fees as affordable to students as possible. However, Crossing All Bridges is now looking at heavy increases to support the growing costs of operating the organization. In the beginning, the fee structure was \$25 per day, but over the last year the rate has been increased to \$30 per day. The current fee structure breaks down to cost each student \$3.75 per hour for an eight-hour day's service.

Based on Crossing All Bridges' fiscal year end at the end of July 2013, the true operational cost of the program is close to \$54 per day. Through our grant writing, fundraising and donations received, Crossing All Bridges subsidizes the tuition costs to balance out the shortfall on tuition. This has potential risk factors for the organization as it continues to grow, putting straining workloads on all the efforts of the organization to subsidize the program.

In the beginning development of the organization, it was hoped that tuition would cover the basic operational costs and other revenue generated through fundraising would eventually go to costs associated with maintenance and the purchase of a facility. We've grown and we've expanded. Now we need more space. We've already fundraised to our maximum. Ideally, to continue, we need to increase tuition, but if we do so we know that families will cut back because they can't afford it. The lack of appropriate financial support to families is crippling our organization.

We will see many students reducing the number of days serviced. Again, it would result in less service for people with developmental challenges, when our goal is to increase services. We're in a Catch-22. There are potential new students who would benefit greatly from the program but face the financial barrier of the tuition fees due to a lack of sufficient funding. Students who started 11 years ago receive the same funding levels today, yet the cost of living has increased steadily every year, requiring families to sacrifice valuable service for their sons and daughters. Some students attending Crossing All Bridges have even had their funds decreased. Five of our students were fortunate to receive Passport funding when it was introduced.

Families are faced with daunting decisions to come up with dollars to continue to pay the fees, especially the families that now live on their Canada pension or retirement funds. As family caregivers age and continue to provide care for their loved one at home, they are finding that the costs to keep them are increasing while their sources of income are decreasing. Many families do not plan their retirement incomes to include the cost of care for a developmentally challenged dependent. An increase in Passport dollars would benefit many people living with developmental challenges.

Our staffing: Crossing All Bridges understands that our best asset to a success is through the people we hire. Over the past 11 years we have found that well-educated and trained employees bring a wealth of knowledge, understanding and passion to their job. The students respond to staff members faster and seem to retain what they have learned. With the overflow of young teachers who have not been successful at getting positions in local school boards, Crossing All Bridges has been privileged to have their talents in our classrooms. The challenge Crossing All Bridges is having is keeping them. We can't compete with teachers' salaries and the salaries of transfer agencies with government funding. We're not able to provide benefits, so we're only able to keep our teachers for a limited time until they can find better jobs elsewhere. They've all got families, debts and things to pay. CABLC feels we do not have a level playing field for offering wages to our employees unless the increase in tuition fees is addressed.

1500

Families that receive government-funded programs are not aware of the cost of their government-funded programs, such as literacy programs or respite. They can't compare a fee-for-service program and a government-funded service that they don't really know the actual cost of, so they're not really sure they're getting the most bang for their buck. The introduction of Passport funding has introduced cost for service, but families are unaware of fair market rates, so to them government-operated programs are free. Families have not had to manage money for service in the past. Passport is a new concept that is taking some time for families to adjust to. Again, they're not really sure what the cost of government-funded programs is. They know that our program costs \$30 a day, and it seems like a lot. An investment in more dollars for Passport would assist with organizations being able to manage the costs of service.

Marketing and training: Crossing All Bridges has made many attempts to reach local high schools in both the public and Catholic systems in regard to transitional planning. There have been small gains in the last couple of years where we have finally been allowed to share our information with graduating students and have been asked to make presentations to graduating students transitioning into the community. More effort on transitional plans by high schools would reduce the anxiety for families and the student moving into life after school.

Being invited to attend community developmental round tables would provide a means for all organizations

that provide services to adults with developmental challenges to be kept informed of current issues. It may also foster partnerships for sharing services. Currently only government-funded agencies sit at round table meetings.

Crossing All Bridges would welcome the opportunity to have members of the government of Ontario come and witness what we offer the adults in Brantford and surrounding areas and show that there is great value in every dollar invested in our program. This could be considered an alternative to college or university for the people we service, while at the same time working to engage adults with developmental challenges in social enterprise employment opportunities.

The need to provide social, recreational and inclusive opportunities for children, youth and adults: Crossing All Bridges believes heavily in this. Our experience is that peer friendships are extremely important for the wellness of all people, regardless of age, race and diagnoses. We all value our peers for friendship and support. We have witnessed a friendship between two Down's syndrome young adults at our learning centre that turned into romance and then to marriage. A young Down's syndrome woman who stopped talking for many years now tries to sing and speak. A 40-year-old Down's syndrome woman, after graduating from high school, stayed at home with her mom for 20 years and became withdrawn, shy and timid, but once registered with the program, she learned to cook, made friends and eventually became the caregiver for her aging mom of 94. This vulnerable population is no different than anyone else. They need social stimulation and they need to feel a part of a group and community to stay healthy. The government can choose to support organizations such as ours.

The elementary and secondary school education needs of children and youth: Students need tools and training to do the job. Classrooms designed for developmentally challenged people require teachers that understand the needs of the students. They need teachers who are committed to keeping informed of current information on the spectrum of developmental findings. Constant attention needs to be given to technology that can assist developmentally challenged people to learn. Schools need to be equipped with these tools, and teachers need to be trained on their operations so students can benefit. In the years that my daughter attended high school, her classroom was filled with whatever was left over from all the department needs, so I highly believe in investing heavily into the current technology that's available.

Teachers who are committed to educating people with disabilities: The special educational hiring policies need to be specific so teachers entering the teaching profession understand that it's just not a backdoor entry system into the teaching profession nor is it an easy last few years to retirement. Teaching a special-ed student should carry a full university course. We could follow cases such as medical doctors and how they go through their training.

The need for a range of available and affordable housing options for youth and adults: Crossing All

Bridges is aware there are needs for group home living models, supported living models and independent living, and that it would be daunting to consider changing the current funding system. We are aware that the government of Ontario has built considerations for innovative models that are based on good business plans with sustainable futures. Living models are as diverse as people's needs and circumstances. In CABLC's strategic plan, completed in 2013, the establishment of a living model solution was considered by virtually all board members to be the initiative that would have the most benefit for members and their families. Wait-lists for the Brantford area are on a crisis basis only, and by that, I mean one of us would die and then my daughter might reach service. She has been on the wait-list since she was 13 years old. We've never been called.

Our health is shaped by how income and wealth is distributed, whether or not we are employed and, if so, the working conditions we experience. Furthermore, our well-being is also determined by the health and social services we receive and our ability to obtain quality education, food and housing, among other factors. These living conditions are often imposed upon us by the quality of the communities, housing situations, our work settings, health and social service agencies and the educational institutions with which we interact.

The Canada Mortgage and Housing Corp. completed a study between 2004 and 2006 that found that family members are the main source of support for almost 80% of adults with developmental challenges. I would assume that's much higher now. They found that individuals with developmental challenges are living longer and that the demand for housing would double over the next 25 years. The study reported a significant gap between the housing needed and the housing available. When families are forced to make the decision to place their loved one in a home, many families are presented with options that do not support the lifestyles of choice. This has forced many families to continue to care for their loved one in their home setting, leaving caregivers the responsibilities well into their 80s.

The Chair (Mrs. Laura Albanese): I have to advise you that you have reached the 20-minute mark, but if you want to make some concluding remarks, please go ahead.

Ms. Debbie Brown: We just hope that you consider our model. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for presenting to us.

MS. DARLENE SMITH

The Chair (Mrs. Laura Albanese): Our next presenter is Darlene Smith. Our Clerk just indicated that she's in the hallway, so she should be here in a second or two. I had no idea she wasn't present; otherwise we could have heard a minute or two longer from Crossing All Bridges Learning Centre. Here they come.

Darlene, please come forward. Thank you for being with us this afternoon. As you settle in, I just want you to

know you have up to 20 minutes for your presentation. If you take less than that, then we'll have time for some questions; if not, we'll be very pleased to hear you.

Ms. Darlene Smith: Thank you.

The Chair (Mrs. Laura Albanese): Go ahead. Catch your breath. If you need some water, go ahead.

Ms. Darlene Smith: Yes, I might just take a little sip before I start because my throat is dry.

1510

My name is Darlene. Thank you for allowing me to come and speak with you today. I am here today to share with you our personal story of raising a child with fetal alcohol spectrum disorder and some of our suggestions that would help other families in Ontario who are also raising children with FASD.

I am an early childhood educator and a home-schooling mom. I have worked in the field with children for the past 24 years, both in formal child care settings and most currently in home child care. In this time, I have worked with a lot of children. Probably hundreds have been through my care. I have seen many children over the years diagnosed with ADHD, ADD, autism and various other developmental disabilities. I have the skills to work effectively with both the children and their families, giving them skills to help them in their journey as families who are raising children with special needs.

With my background, becoming a foster home for newborn babies was natural for us. Helping the little ones who come into this world drug-addicted and alcohol-affected was both challenging and rewarding.

We were blessed to be able to adopt one of our foster babies, and she is now six and a half years old. She is our life, a joy, and full of enthusiasm. What I was not prepared for was the challenge of parenting this little dolly. I figured with my background, my skills, my personality and an amazing, supportive family, this would be no problem. I've worked with lots of children with special needs.

Up until she was five, I was using all my skills to help her as she struggled with social interactions, hyperactivity, impulsivity and emotional outbursts. Nothing I tried was working. My skills were useless. I was starting to feel like a failure to this child. What was I doing wrong? Society and those watching, I'm sure, were thinking the same things: "Look at that ECE mom. She can't even parent her own little one."

In January of just last year, I was Googling, trying to find out what possibly could be happening for our little one. We knew that her birth mother had made some bad choices when she was pregnant, but I guess we were naive. I then came across an online assessment for FASD. I printed it and filled it out, and my heart sank. I answered yes to every question. The light bulb went on.

Trying to find out how to have her diagnosed was my next challenge. Off we went to the pediatrician, who listened to our concerns, then referred us to a local agency, knowing that there was a new diagnostic clinic in our city. We were turned down and told we had to exhaust all other resources in the city before this agency would take her case. Now where do we turn?

I called another family and children's centre here in London in February of last year when I was finally hitting a crisis point, not knowing what to do. Who do I turn to for support? We finally had an appointment with an intake team. They gave us behaviour techniques that I had already tried and knew would not work for her. Cause and effect, reward charts and stickers are all things I had tried in the past, but because of her organic brain damage, these techniques do not work.

Back to Google I went for how to get a proper diagnosis of FASD in Ontario. I did find a list of clinics, but with most of them you had to live in the region where the clinic was offered. The waiting list in London was much too long, as it is a pilot project.

There was one exception, and that was a clinic being run out of St. Michael's Hospital in Toronto. I made the call and was told that if we had a pediatrician fax a referral, we could be seen as early as June of last year: 12 weeks. Wow. I thought that was amazing. So we got the referral and the appointment booked.

Our daughter does not do well in the car for any length of time, so we chose to take the train to Toronto. We had two appointments, one in June and one in July, two train trips, two days off of work, and we came home with a diagnosis of alcohol-related neuro defect.

FASD is the umbrella term, and under that are levels on the spectrum based on facial features alone. We all assume that if there are no facial features, it cannot be FASD. Did you know that the facial features that we commonly associate with fetal alcohol spectrum disorder are only affected in the first 21 days in utero? After that, any drinking that happens causes all this brain damage to these little ones without the facial features. So now we have a population of children living in our communities who look very, very normal but have a very serious brain injury. It is completely invisible.

So now where do we turn? There are resources for autism, for children with physical or intellectual disabilities, but at this point, FASD is not recognized by most of these agencies, and therefore we're not able to tap into their resources. This goes for children, youth and adults in our communities who are living with this brain damage.

We have navigated our way, trying to learn as much as we can through online resources, webinars, and most importantly, I have connected with adults who are successfully living with FASD. These are the people who have lived it, and I have learned so much from them, more than any book, article or video could ever teach me. I am urging you, as a committee, to find these people in our communities and connect with them. They are the ones who can help us figure out the services that they need.

Now my family is on this journey, a very lonely journey at times. No one really understands what our day-to-day life is like. They see a beautiful, blonde, blue-eyed little girl who is full of life. We see the same, but what others don't see is the constant, behind-the-scenes managing of her behaviour, emotions, sensory dysfunction and social interactions. Our lives revolve around

supporting our daughter 24 hours a day, seven days a week, as we are home-schooling her.

We are her external brain. The cognitive impairments in children and adults with FASD can cause them to have poor memory, lack of impulse control, poor judgment, and difficulty with cause-and-effect reasoning. This means they often need support from others to help them think through their decisions, behaviours and consequences, as well as help them remember their routine, schedule, and how to complete tasks assigned to them. In other words, those living with FASD need a trusted person to act as their external brain 24/7 through their complete lifespan.

As a family in this situation, finding respite and support is almost non-existent in our communities in Ontario. Wait-lists of upwards of three years—and even then, getting the right fit for our child is a tough one. People are not educated about FASD to really understand how to work with them.

I am urging you to step up to the plate to educate our communities, medical teams, professionals and even parents about the horrible effects of drinking during pregnancy. No amount is safe. It sickens me to read articles as recently as last week in our local paper stating that drinking 15 drinks in a pregnancy is okay. I am telling you, as a parent raising a child who is affected by alcohol, that this is unacceptable. The labelling of alcohol bottles, advertisements promoting zero drinking, commercials—anything that gets the word out there that drinking in pregnancy is damaging these babies in utero. It is the most preventable disability in our communities.

I am also asking that this committee take a look at the diagnostics for FASD. We need these clinics in our communities to receive full funding, not just pilot projects to see if they can stay. They need full funding now so they can carry out this very important role.

We need to educate our medical professionals, teachers, social workers and anyone working with these children. Just because there are no facial features does not mean a child is not suffering from FASD. FASD needs to be added to all the warning sign checklists and diagnostic tools. ADHD is the first thing people see in our little one; when they see her, it's what they think she has. Yes, she's high energy and can appear to be very defiant, but the impulsivity, hyperactivity and defiance are symptoms of her FASD, and are symptoms that signify that she is not able to cope without her external brain.

She does not process our words. Her auditory processing is impaired and therefore she hears one out of every four words we speak. So this speech, to her, would be: "I'm ... you ... go ... now"; that was: "I'm asking you to go to the bathroom now." She hears one in every four words, so communicating with these children, these adults, is very specific on how we can communicate with them.

Her concept of time is pretty much non-existent. Five minutes, one hour, one day, one week, are all very abstract to her, no matter how much I've worked with

her, and therefore make our interactions quite difficult. Her short-term memory is affected. Each day, the same teachable moments, the same things—she does not remember from day to day. That's why she needs her external brain. For these reasons, we have chosen to home-school her, in order to give her an environment that she can be successful in, but not all families are as blessed and lucky to offer that environment.

I have heard from so many parents in our FASD support group that trying to get the proper support in school is not possible. There is not enough of an understanding of FASD and how it impacts these children from day to day. There are very specific strategies that can be used to help them, but teachers and school systems are not aware and/or are not able to provide the time and resources needed for these children. Now is the time to invest in them. Now is the time to put money into early diagnosis and keep these clinics open so that they can get properly diagnosed, making sure they are in homes that are trained to help them be successful, in school programs that understand and support the primary disabilities of FASD, and in communities that will support them 100% just like any other child who has a disability. By having these things in place, secondary disabilities like frustration, acting out, irritability, mental health disorders, homelessness, alcohol and drug addictions, disrupted school experiences, trouble with the law, incarceration, inappropriate sexual behaviour, problems with employment and dependent living can be prevented, if they are given supports and external brains to help them.

1520

Go to the adults who are living with FASD. They are our best teachers and educators on this. Find out what life has been like. Most of them have been through the trenches because they were never diagnosed when they were young. They have dealt with drug addiction and alcohol addiction but have come through and got proper diagnoses, finally. Some of them are 40, and the light bulb went on for them, and they are now able to get those supports in place. How sad that it took that long. We are in a time when we can find these supports early and get these children diagnosed.

These children as well as adults in our communities really do have a serious disability that none of us can see, and it needs to be acknowledged. There are many children in foster care and adoptive homes, which do break down because of these behaviours, and the parents just don't know what to do with them, and adults living in our communities who are either misdiagnosed or diagnosed and not being given proper supports to help them live a successful life. It's time for agencies and government to take a hard look at what we can change to help make this invisible group of people in our communities live supported and successful lives.

A child will not grow out of fetal alcohol spectrum disorder. However, early diagnosis and intensive intervention can make an enormous difference in the lifetime prognosis.

Do I have a few minutes?

The Chair (Mrs. Laura Albanese): Yes, you do.

Ms. Darlene Smith: Okay. I'd like to introduce to you Emma.

"My name is Emma, and I am six years old. Can you believe that? Six already.

"Don't you think I'm cute? On the outside, I looked just like any other baby: tiny, sweet, and oh, so snugly. I was adopted when I was a baby because my birth mom was too sick to take care of me. She wanted me to have a loving home, and I'm so glad I was adopted. I have the best mom, dad and big brother.

"I am loving life. We are a home-schooling family, which means I get to spend a lot of time with my family doing really cool things. We have a home-school group, too, that we do field trips with. It is a lot of fun.

"I love to dance and sing. You can usually hear me humming and singing even when I'm playing or doing school work. I love to colour, paint and make amazing creative messes.

"But there's something about me that you don't know. When my birth mom was pregnant with me, she made some not-so-great choices. She didn't take very good care of herself and did some things that mommies are not supposed to do when they are pregnant. Because of these choices, I have something called FASD; you pronounce it just the way the letters are said. That stands for fetal alcohol spectrum disorder. It sounds pretty confusing, but I'm going to tell you what it means.

"I know I look just like any other little six-year-old girl, but there's something about me on the inside that you can't see: how my brain was damaged before birth by my birth mom drinking alcohol. You can't see the tangled connections and all the little empty spaces in my brain. Unless you can see inside my head, you can't see that I have FASD. It is an invisible disability.

"But I do know what you can see, and that is how silly I act when I am out in public, like visiting with family or friends, at church or at the mall. You can see that I have a hard time controlling myself and I appear to be misbehaving. You may notice when I get out of control and lose it, and that happens when things get to be too much for me to handle. Some people think that my behaviour is a problem and I'm just being a bad kid. The truth is I have FASD. The doctors told me that what that means is my brain damage won't get any worse, but it won't get any better either; it's forever. I need a great team of people in my life to help me be the best that I can be.

"You can always hear me because I talk a lot to anybody who will listen. When you ask me a question, an answer pops out, whether it's true or not. I have a really hard time understanding what others are telling me. I really need you to help me and to be super patient with me when I am like this. I'm not doing it to be rude; I usually do it when I feel overwhelmed and cannot handle the situation.

"There are some things you can do to help me: take my hand, talk with me. If I interrupt you, please do not get frustrated and walk away; gently tell me you have

something really neat to tell me. I love hearing funny stories. If you distract me with something new, I can usually pull myself together.

"Because of my FASD, I can't remember a lot of things from day to day. I know my mom and dad say it feels like every day we go over the same things. They probably think I should learn from my mistakes, but I can't. It's not that I don't know the rules; I do. It's not that I don't understand consequences; I do. I just can't make myself do what I know I should do. I don't know why; I just can't. That is the part of the brain that is damaged, the part that links the left and the right side together. For me it is so frustrating because I so badly want to make good choices, but when I feel overwhelmed, I can't.

"Everybody can see that I'm friendly and affectionate. I love people and I love making them smile, but nobody can actually see how lonely I really am. I have lots of friends, but they never come over or call for play dates. I don't have a best friend, but I pretend like I do. If someone just smiles at me, they are my friend. I have a hard time understanding how to behave in social situations like play dates or when I bump into people I know. If I see you, I get excited really quickly. Please hug me, love me and be happy to see me too. I need you to be super patient and kind in order to make me feel safe.

"I have a very free spirit. I do not understand my personal safety. If my parents let me, I would just go off and explore the world without them. They know that is not a safe choice for me and they need to supervise me at all times. Please do not be hard on them. They know me best and need to watch out for me because I will make silly, unsafe choices. The job they've been given is a huge job but I'm so thankful they're patient with me. It's going to help me a lot to have the support of family.

"I sometimes have trouble remembering things. I've heard my mom call me Dory, like in Finding Nemo. She has short-term memory loss. Even when people tell me things over and over, I still forget. I have a problem processing information, especially when it's busy around me, and then it may look like I'm being a bad kid again. This is where I need you to help me too. I need people to give me reminders and guide me through some of the busy times.

"My parents and brother have a pretty hard job. They need to be my coaches in life and need to be with me wherever we are. I do not understand safety and would just run if left to do that. They are going to take turns helping me when we are out, helping me to stay in control. They're not being over-protective; they're being supportive and helpful to me. I do not try to make people mad. I don't want to be seen as being bad. I just need help to interact and behave in different situations. Please encourage them, as they have been given this lifelong task of helping me. I am so thankful to have them.

"I want to be appreciated for the good things I do and who I am. Do you notice those—my smile, my friendly personality and my helpful nature, the compliments I give out graciously, my singing, my dancing and my love

for everyone? I just want to be accepted and understood. I hope that you knowing about FASD will help you know more about who I am. I need you to care even when I act like I don't. I want to be respected and I need you to be a good role model for me so I can learn to be respectful too. I need lots of love and patience as I grow, so if you see me having a hard time, please help by being with me instead of walking away. Hold my hand, sing with me, laugh with me, and let's make great memories."

We put this book together for family and friends and those who come in contact with Emma to have a better understanding. Like I say, it's completely invisible, and she's one of thousands. If you saw her in here, you'd think, "She's a little out of control." She's not; she just needs help to be in control, and there are thousands of them. This little one is blessed; we're able to do this for her. But there are families and supports that are not in place, and then we have adoption breakdowns and we've got children suffering and adults going into their adult life.

So keep those clinics open and fund them completely, please. It will pay off.

Any questions?

The Chair (Mrs. Laura Albanese): Thank you. Unfortunately, we're out of time for questions, but it was so much more interesting to be introduced to Emma and to hear her story, and you read through that booklet. It's really amazing what you are doing. Thank you for presenting to us and for making us aware of this. We really, truly appreciate it.

Mr. Mitze Hunter: A very quick question: Your book is just for your personal family and friends, or is it—

Ms. Darlene Smith: What I can do—is there a way I can email this to your committee?

The Chair (Mrs. Laura Albanese): Yes, you can.

Ms. Darlene Smith: Okay. I can email you, because I just want to take out a couple of her pictures because of her face at the front. I shall email you an electronic copy of it.

The Chair (Mrs. Laura Albanese): Yes, you could email our Clerk, Trevor Day.

Ms. Darlene Smith: Okay, perfect. You can purchase them for \$150 each, just to add to your collection. We'll raise money for the clinics.

The Chair (Mrs. Laura Albanese): Thank you.

COMMUNITY LIVING LONDON

The Chair (Mrs. Laura Albanese): We now call on Community Living London to come forward. We have three people who are moving up. Good afternoon; welcome. We look forward to your presentation. If you've been sitting in the back, you know you'll have up to 20 minutes to do that. Please introduce yourselves, starting with your names and your titles. Thank you.

1530

Mr. Jim Hewett: Thank you very much for inviting us today. My name is Jim Hewett. I'm the chair of

Community Living London's advocacy committee, and I'm a member of the CLL board of directors. I'm also the parent of Kevin, who was born with Down's syndrome. He is in the room today.

I'd also like to introduce two other members here today. Murray Hamilton, on my right, is also a member of Community Living London's advocacy committee, and Michelle Palmer is our executive director.

We commend the select committee for its commitment to examine the urgent need for a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability. We look forward to contributing to the development of a comprehensive plan for the developmental services sector, and we're here on behalf of people with an intellectual disability and their families.

As you are aware, there are over 19,000 people with an intellectual disability waiting for service in Ontario. The developmental services sector is in a state of crisis. This sector has been underfunded for far too long, and this has created the critical situations that you have heard about from families who are facing a lack of residential options, limited community participation opportunities after graduation, limited resources to secure employment for long-term success, lack of transitional supports from childhood to adulthood, and aging parents who are no longer able to care for family members who live with them. We could go on.

As you are aware, based on statistics from Developmental Services Ontario, South West Region, there are over 12,000 people in Ontario waiting for residential supports. In this region alone, London-Middlesex, we have over 300 waiting for group living supports and over 200 waiting for supported living arrangements. In London-Middlesex, there are over 190 waiting for in-home community participation supports and 150 waiting for social and recreational supports. As well, there are 100 waiting for employment training supports. In Ontario, people with an intellectual disability are 70% unemployed, even though 80% of people with an intellectual disability can and want to work competitively.

Today we will focus on solutions so that people with an intellectual disability and their families will begin to receive the supports and services needed to meet the significant challenges that they face.

We'll keep our presentation short to allow the maximum time for questions.

We would like to suggest the following five actions that would go a long way to resolving the issues confronting families and people with an intellectual disability.

Mr. Murray Hamilton: The first action that we would like to recommend is that the government formally recognize the legal rights of people with intellectual disabilities.

It is generally recognized that government has a responsibility to protect the rights of and to provide services to all its citizens. One of the values inherent in Canadian society is the belief that it is important to

collectively care for people who are unable to care for themselves and that elected politicians are expected to carry out the will of the Canadian people in this regard. A society is judged by how well it deals with its most vulnerable members.

We are asking that the select committee recommend to the government that it formally acknowledge its responsibilities to vulnerable citizens by amending the Ontarians with Disabilities Act, to grant them the legal right of access to the services that they require.

De facto, these needs were recognized by the government of Ontario more than 170 years ago when they established facilities for people with intellectual disabilities in Orillia, Ontario. Over a hundred years later, they recognized that facilities were not the place for people to live, and co-operated with community agencies and families to create a broad network of support services for people with disabilities.

Regrettably, in the last 15 or 20 years, the government seems to have forgotten its responsibility to citizens living in our community. Our community network is virtually stalled.

We urge the government to rebuild this partnership between the government, families and community agencies, to create a service system that responds in a timely manner to the particular needs of individuals and families.

Secondly, we're recommending the development of a multi-year plan for the developmental sector, to develop a long-term plan to address all of the service needs that have been identified throughout the course of your hearings. This plan would necessarily require a commitment of hundreds of millions of dollars over the next decade to meet the critical needs of people for residential support, day service options, in-home support and employment.

As an immediate priority, we're supporting the recommendation from the initial report entitled Ending the Wait that the critical needs of adults whose parental caregivers are over the age of 70 be addressed within the next 12 months. Now this government has had a good track record in developing multi-year plans to address very serious and long-term issues. Between 1982 and 2010, there were a number of multi-year plans in which governments and agencies and families worked together to close facilities. This was an initiative that took 40 years. The problems confronting us today are just as great, if not greater. So we recommend that the government take the long view here and develop a number of multi-year plans to address these issues over time.

Continuity of supports from birth to death: to reinstate immediately the services to young adults who reach the age of 18 which were recently arbitrarily suspended, thus leaving families without the necessary resources upon which they have become dependent for in-home support and respite care. This decision reflects the lack of coordination of services between the Ministry of Children and Youth Services and the Ministry of Community and Social Services. We recommend a reversion to the

time when a single ministry would be responsible for the provision of community support services for all people with intellectual disabilities from birth to death.

Our fourth point is fair compensation for workers. We applaud the fact that in recent years, the Ministry of Community and Social Services has participated in a human resource strategy that is focused on agency-based training requirements, core competencies and shared interests. However, in order to maintain a high standard of service, employees in this sector must be compensated fairly. The sector cannot have good services without skilled employees and positive employee relations. It is interesting to note that direct care professionals in this sector today are earning a similar wage to what government workers who performed the same duties earned 10 years ago. We recommend that the government commit itself to providing annual compensation consistent with increases to municipalities, school boards and hospitals—informally known as the MUSH sector.

Our final point is that we work to break the cycle of poverty for people with intellectual disabilities, as most people are living well below the poverty line as defined by LICO, the low income cut-off, now pegged at \$16,753 for a single person living in London, Ontario. It is not well understood that people with intellectual disabilities are dependent on their ODSP for all of their personal needs: for food, clothing, shelter and transportation. These allowances over the past 20 years have consistently lagged behind the rate of inflation. Currently, ODSP recipients have lost 18% of their purchasing power relative to inflation since 1995. Consistent with the recommendation of the social assistance review, we are recommending an immediate increase to ODSP income support to reach LICO levels and a commitment to link further ODSP allowances to the rate of inflation.

With respect to employment, we strongly encourage the government to develop strategies to increase employment for people with intellectual disabilities. We have provided a link in your package that will take you to a video that demonstrates the impact that strong relationships with business and the provision of relevant training for people has on long-term employment success for people with intellectual disabilities. We recommend that the first \$700 of earnings be exempt from clawbacks and, beyond that, ODSP benefits be reduced by only 50% of earned income, and that this exemption keep pace with inflation. The government must make sure that its most vulnerable citizens at least meet the LICO cut-off before reducing any further earned income.

1540

Mr. Jim Hewett: In closing, we wish to emphasize the government's responsibility to acknowledge the inherent rights of citizens with intellectual disabilities and to provide the necessary supports and services to enable these persons to live full and meaningful lives.

We want to acknowledge that this ministry has a track record of developing a series of successful multi-year plans over the three decades that resulted in the closure of all Ontario institutions. These plans were developed in

consultation with families, community agencies and government.

We would like to remind government that their responsibility for people with intellectual disabilities did not end with the closure, and encourage them to honour the commitment that was made during the closure of institutions by providing adequate funding for community service and support options.

We also strongly encourage the re-commitment to a multi-year planning process that consults broadly with families and agencies to achieve mutually determined goals.

Thank you. We're willing to take any questions.

The Chair (Mrs. Laura Albanese): Thank you, and we have about three minutes for each party for questions. We will start with the government side.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you very much for your presentation.

The focus of our committee is to develop a comprehensive strategy that will provide the necessary supports for people with developmental disabilities across a lifetime and across ministries. You have put forward a number of very solid and well-thought-through recommendations. If you were to prioritize, what would you put as your most important recommendation for us to consider?

Mr. Jim Hewett: The very first thing is the wait-list. The wait-list has to be dealt with. There's no question about that. It's huge.

The second thing is funding for the sector. The sector has been underfunded for many, many years without the financial support of government to this sector. Working with the families, working with the local community and working with government together, we hope that we can move forward on this.

But those are just a couple of things. We've given you five things that we really are very strongly endorsing here. But the wait-list and the funding—they're critical. They're critical to do anything by any organization within this province.

Ms. Mitzie Hunter: One of the challenges that we're hearing from people presenting today and as we're listening through these hearings is the transition moments, in particular, transitioning from the services from the children's programs into adult services.

Mr. Jim Hewett: So from Special Services at Home to Passport funding—we call it "falling off the cliff." That's basically what it is.

Ms. Mitzie Hunter: And it could even be, just beyond that—I guess what I'm looking at, in terms of your experience over many decades working with people with disabilities, is, what are some of the things that we can do to strengthen the system and make that transition a much more successful one in the areas of employment, in the areas of community inclusion and some of the things that we're hearing?

Mr. Jim Hewett: Well, I think the first thing is they don't need to drop off the list once they turn 18. If there are supports in place for that individual, the individual

has been identified, then it should transition from Special Services at Home directly into Passport funding. That's one of the first things.

Then, when we get into the person leaving school, once again, they drop off another cliff, because the supports are no longer there. So we have to be able to transition from that school environment into either an employment environment, a community access program environment or some type of supports for the individual so that they can meet their goals in life.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Mr. MacLaren?

Mr. Jack MacLaren: Your five ideas are great. I think here we all understand that everything kind of hits the wall, and the inevitable question is, "How do we pay for all this?" So I want to ask you on that part, because that's a question that we have to answer, or all of this is just academic exercising.

So do you have any idea—and that might be a tough one—how much money we would need to fix these five things, and how should we and where should we access that money? Would it be increase taxes, cut other programs, look for private money or what?

Mr. Murray Hamilton: It's very difficult for us to put a concrete number on it, but we feel that it's pretty simple for the ministry to be able to do that. They know currently how many people they're supporting; they know how many people are on the waiting list. Take the average cost of the persons that they are supporting today and add that number to the corresponding waiting list number. It is hundreds of millions of dollars. This problem has been allowed to languish now for 15 years.

Frankly, as we have said, we believe that these are legal rights; these are legal entitlements that people have. I believe the government has a responsibility, out of its tax base, to fund these services. The fact that they have not done so for 15 years just has made the problem more difficult, but it is not going to go away. As we have pointed out, there are people in their seventies and eighties looking after their disabled children. It is important that the government acknowledge that this is a role and then put a long-term plan in place to fix it.

Mr. Jack MacLaren: Well, I agree with you and I think most of us do acknowledge it's a problem. We've neglected this area for a long time, and the falling off the cliff is a classic example of a huge problem—aging parents etc. But at the same time, most of us also understand that the general population is kind of taxed out with hydro bills rising and taxes rising and property taxes rising. To raise taxes, as a straight answer, is not just a real happy solution either, because often you're taxing the same people we're talking about here today, plus everybody else as well.

Mr. Murray Hamilton: It's not for us to discuss how the government has spent its money over the last few years—

Mr. Jack MacLaren: That's too easy.

Mr. Murray Hamilton: It's not for us to discuss that. However, we know that money can be found when the government wants to do stuff. These are legal rights that people have. The government has to find this money. If it has to raise taxes to do it, so be it.

Mr. Jim Hewett: We need to make it very clear that there's a huge bubble brewing. All the adults and children being supported by parents at home right now are aging. You've got a huge baby boomer population that is supporting these individuals at home. They are between 50 and about 66 years of age. They're getting to the point where they can no longer do this. This bubble is going to break at some point in time, and it's going to break in the not-too-distant future.

Ms. Michelle Palmer: If I could just also talk a little bit about pre-planning, I think right now the response is governments reacting based on crisis. When families just can't do it anymore, then all of a sudden somebody becomes a priority.

Any kind of emergency plan costs more money. If we can do concrete plans with families in advance, then you can look at, for example—and this is not the only option; I want to be clear that we're supportive of family options, any options on the table. But if I have to plan for one person today, it's going to cost a lot more money, because that one person may still need 24-hour support. If they have three friends that they'd like to live with as well, four people supported together could cost the same amount. Right now it's a knee-jerk reaction based on crisis response, which costs more money.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: That leads me to another question for research. We have questions where we haven't yet received a response from MCSS. They haven't given us wait-list numbers. You folk kindly have, but we haven't gotten that from MCSS.

Number two, we've asked for the number of people with developmental disabilities that are in long-term-care homes, in prisons and in hospitals. The reason we asked for those figures is that that's ridiculously expensive care, as you've said, that shouldn't be happening. What should be happening, of course, is the kind of care that you've advocated here. So again, I ask for these figures from MCSS or health or somebody. I mean, we just haven't got them, and without them it's hard to do our work.

The only other question I have for you is the DSO. You hadn't talked about that in your presentation. What's your experience of it?

Mr. Murray Hamilton: Well, our experience basically is that we have created a planning mechanism but there's no money to plan. So it's easy to get very angry at the DSO, and like everybody else, we are, but until such a time as this body has some money to actually create services, it has just become kind of a bureaucratic nightmare.

I would say that the one mandate they do have is to provide good, solid information; we're not getting it. We're not getting good waiting list information. We're

not getting any rolled-up information, as you have just said.

I just want to end up on one positive note. We've talked about how big this problem is, and it is huge. However, we do believe that at a certain point you are going to max out. We will reach the point where we can support all individuals with intellectual disabilities and the system will be self-sustaining.

1550

Unlike the Ministry of Health, which will never stop asking for money, this service sector, if everybody is served—we're at the point where the number of people who are dying is going to be equal to the number of people who are coming into that system. We're virtually there now, except that we've got this great bubble of people who aren't getting any service at all.

I think that when the government is doing its planning, sometimes they get nervous because they think this will never end. This will end if it's funded properly.

Ms. Michelle Palmer: Can I just jump in about the DSO? I just want to really stress that the problem in our sector was here before the DSO, and the problem will be here without the DSO. So I just want to clarify: The DSO is not the problem.

Ms. Cheri DiNovo: But it takes money to—

Ms. Michelle Palmer: Correct.

Mr. Jim Hewett: You were mentioning, too, the number of people who are in long-term care. Actually, in the Ministry of Health presentation, 4,500 residents in the province who have a developmental disability are currently living in long-term care.

I wouldn't look at the Ministry of Health as the solution to the problem. This is from the Toronto Star last June: "The number of people waiting for beds jumped by almost 85% between 2005 and 2012, when there were 19,000 waiting for placement, according to the provincial auditor. But the number of beds increased by only 3% during that time."

We had 2,000 Ontarians in hospital beds, waiting for LTC placement, in March of last year. Some 90% were placed within 495 days, with waiting lists being the longest for the hardest-to-serve patients, including those with dementia.

So the Ministry of Health is not going to be the answer to this. They have their own problems. But it can be solved with a single ministry, from birth to death, dealing with developmental and intellectual disabilities.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us. We also have received some answers from the ministries to date. Some are included.

Interjections.

The Chair (Mrs. Laura Albanese): The researchers told me that some of them are included—

Interjection: In the back.

The Chair (Mrs. Laura Albanese): —in the back. Yes, I went by the front as well, but in the back, they are included—not all of them, but some.

Ms. Christine Elliott: Madam Chair, I'd just ask for a little bit more research to be done on the basis of some

of the excellent information that we got from this presentation. We probably have this information in one of the presentations we've already received, but if we could get some indication about the number of people who are receiving ODSP in Ontario—because there was an indication in the presentation that there's a 70% unemployment rate, even though 80% of people have indicated that they are willing and able to work competitively. I think if we take a look at that and figure out the number of people who potentially could be working but who, through no fault of their own, aren't working right now, we could probably find the savings from a lifelong time on ODSP that isn't perhaps necessary for some people—to put it into the supports and services for people who truly need them.

The same thing—we could probably quantify by taking a look at the number of people who are inappropriately placed in hospitals and long-term-care facilities right now. By sorting people into where they should be economically and socially, we could also achieve, I believe, significant savings to put into the supports for those people who are truly vulnerable and really need help.

The Chair (Mrs. Laura Albanese): As you said, it's more about planning and doing it right.

Ms. Michelle Palmer: None of us want to live in long-term care for our entire life.

The Chair (Mrs. Laura Albanese): Yes. Thank you very much for coming this afternoon and for the information you provided. It's very valuable to us, as a committee. We appreciate it.

MS. KATHLEEN GIFFORD

The Chair (Mrs. Laura Albanese): We'll now call on Kathleen Gifford. You can choose the chair you like best.

Ms. Kathleen Gifford: Thanks.

The Chair (Mrs. Laura Albanese): Good afternoon, and welcome. You may begin any time you feel ready.

Ms. Kathleen Gifford: My name is Kathleen Gifford. I'm employed with Ingersoll Support Services as a social network facilitator. I am also an independent facilitator, hired by families, and am currently working with two families. I am passionate about this work because I have a son with complex autism.

We use the phrase "complex autism" where others would use "low-functioning autism." Our son has a developmental disability and is non-verbal. However, he does have a lot to say. With these labels and a strong desire to communicate, he is often frustrated. The combination breeds a severe anxiety resulting most often in self-injury. So I thank you for the privilege and honour to present and introduce my son to you today. I am very grateful.

The story that I'm going to be telling you is from my son's point of view. He has indicated with his iPad things that he wanted me to mention and chose the many pictures and artwork that we have in this. I wish he could

sit here beside me but he cannot tolerate that at this point in his life.

David John Lane Gifford: He wanted his full name in there and he wanted to let you know that his mom would be speaking for him. He is 18.

"I am 18 years old and the youngest in my family. I have two sisters. The best part of having older sisters is have two brothers-in-law. I am an uncle"—He wanted pictures of his niece and nephew in there—"Genevieve is five and is going to be a big sister in about a week"—so I promise not to procrastinate here. Rowan Matthew is two and "is going to be a big brother in the summer."

"I communicate in many different ways. I use an iPad with Proloquo2Go and some sign language. Here I am pointing to tell my father which way I want to exit the park."

And of course, he wanted me to talk about McDonald's. This is a new skill that he has just developed, to be able to go into McDonald's and place his own order. Sometimes he can even sit inside to eat it.

"When I was a little boy my dad taught me to use songs and nursery rhymes to teach me sign language. I was inspired by the Helen Keller movie to learn sign."

"Communication has always been difficult for me and lots of times my message would be misinterpreted or completely missed all together. The mistakes quickly led to self-injury. Self-injury became so commonplace that people at school would ignore the message completely. People began to think the self-injury was just the makeup of my disability. School was a lonely, painful place. This is where depression and anxiety moved in."

"My family always believed in me. Here I am with my sister. We love to walk together. Walking unlocked my anxiety the same way music unlocked my expressive communication. I began to walk every day. On these walks, I started to learn about life. More importantly, my community started to learn about me. My vulnerability began to fall away and was replaced with people who knew me and liked me. I learned to trust people."

"I began to enjoy life, and my parents invested in my abilities. I began to advocate for myself. It is important to define your own day, your own life." As his parents, this is something that we weren't sure that David would ever be able to do, so we're thrilled that now he's able to access some things for himself that we weren't able to access for him just by exerting his power.

"These walks have shown people how much I know and they trust me that I know it—things like personal safety. I know I have to wait for trains, look both ways before I cross the street, how to operate the stop lights and what they mean."

"I have learned that my walks are more enjoyable if I can make purchases, so I learned to carry a wallet, to make a financial transaction, to look for a checkout in any store. I opened a bank account and learned to use a bank machine."

Here's a picture of him using his iPad to order some French fries, operate the stop light, wait and know what it means. These sound like mundane tasks but up until this

point, a lot of people in his life didn't believe that he had any abilities whatsoever.

"People in the education system believed I had nothing to contribute. My existence became meeting criteria to remain in a behaviour classroom. My self-injury soared to above 600 blows in a half a school day. My parents hired an educational assistant over the summer months, and she witnessed the story that my parents were saying. Finally, someone who was not family believed I had a contribution to make." When she returned to school in September, she "began telling everyone what I could do. I still had to remain in a classroom for half the day and could do co-op every afternoon."

1600

The classroom that my son was placed in was a behaviour classroom that had only four people in it, none of them verbal.

"This is where I began teaching my parents. Life had to be real, and I would rise to the challenge to learn. They learned that I need certain things to feel safe and supported. I need a lot of physical activity to keep the anxiety at bay, I need two people with me to feel supported, and I need to have real relationships in my life. It turns out what I need is what everyone needs: an everyday, ordinary life where we can experience and participate in full citizenship.

"My schooling now is full-time in the community." That's at risk. The board is still trying to figure out a way that that can happen. Right now we have an application in to the Thames Valley District School Board for supported alternative learning, and we should hear next week if this schooling can continue for him. He meets the support outside of the school, and they leave the school from there. He's able to do that without self-injury. If he needs to go inside the school, he simply cannot do that anymore.

"I took everything I learned and went to Canada's Wonderland." Again, this sounds like nothing earth-shattering, except he could make it relatable and function in it—without going on any of the rides; that didn't interest him anyway. But he was able to do all the skills that he learned in his hometown: making purchases and eating in restaurants. He was able to do that in a new place, and that was thrilling for us.

What has been happening after almost a year and a half now of the walking and the co-op is, he's now showing us that he has more capabilities and more interests. He's now learning to read, which sounds a little bit ridiculous since he's 18 and almost finished school, but we're thrilled that it has shown up now. The picture of the dragon gate is just an example of his very unique interests. This is a literacy project that he was doing.

What's next is employment possibilities. He always notices garbage on his 12-kilometre walks, so we are approaching parks and recreation in the spring to find employment for him.

We hired an artist to spend time with him. "Nelle ... walks with me every Tuesday morning and photographs everything that catches my eye.

"I look at the photos and choose the ones I want reproduced.

"Nelle paints them with oil or watercolour." She does stone carving as well. Here's a process of the photograph that he chose and the reproduction of the art. There are a couple of examples of that.

This is all to show you that we rely heavily on self-administered individualized funding. We have a complex needs budget of \$29,000 a year, which is a nice amount to do a little bit with, but it's really only the tip of the iceberg. David aged out of Special Services at Home last month, and we lost \$10,000 in his budget there. Since we adopted our son at the age of three—we had a subsidized adoption, and in June he lost \$12,000 to his budget there.

David is a man who requires supports, education and all of his resources to be customized. He requires two support workers to be with him. We hope that this will change. This has been a development that came up in the last two years, where we had to add the second support person. We hope that it's only for a time while this massive learning is happening. He's a pretty big guy and he has huge impulses, so to be safe right now, we need the two people and that costs a lot of money. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for sharing all of this with us. We have about three minutes for each party for questions. We're back at the PC Party.

Mrs. Christine Elliott: Thank you very much for coming forward and telling us David's story. I'm just wondering where you are in funding right now. Are you in that transition phase where you're applying now to get back the \$10,000 that you immediately lost? How is that being dealt with?

Ms. Kathleen Gifford: I don't really know where to go to fight for the funding that is lost. Thankfully, David has the complex needs funding. That stayed with him, so the \$29,000 will stay with him, but we're just going to need so much more than that. It's fairly evident that David is going to require 24-hour support into the remainder of his adult years. So, yes, the fight would continue for more funding, even to recover some of what was lost. We tried to get children's aid to stay committed to him until he was 25, but that was a very firm, fast "no."

Mrs. Christine Elliott: Can you tell me what other supports are available in your community if, for example, you are not able to continue to support David at home?

Ms. Kathleen Gifford: Well, we're in the wonderful process right now of DSO. We're halfway through the process. It's fairly dehumanizing. I guess you become part of the huge wait-list that was just talked about prior to that. Thankfully, David has family members with him. It's not really a plan to go to a group home. David is going to do much better on his own. We are in the process of setting up a micro board around him—I'm not sure if people are aware of what that is—just to protect his voice and keep it strong. He has a lot to say, has a strong way to say it but at the same time, with being non-verbal, it's very easily stifled.

Mrs. Christine Elliott: Would that be similar to a circle of support—the micro board that you’re speaking of?

Ms. Kathleen Gifford: Yes.

Mrs. Christine Elliott: That seems to be very helpful in terms of putting together supports, both—because they don’t all have to be paid supports, of course—lots of unpaid, informal supports that are also extremely important in a person’s life and allow them to be able to articulate their needs, and for other people to help them achieve their goals.

Ms. Kathleen Gifford: Right, and probably the best way to have those natural supports around them, around David, is with the independent facilitation, which really isn’t something that’s normally offered at this point.

The Chair (Mrs. Laura Albanese): Thank you. Miss Taylor?

Miss Monique Taylor: Thank you so much for your presentation today. This caught my attention here: David was adopted.

Ms. Kathleen Gifford: Yes.

Miss Monique Taylor: Did you continue to keep other people within the children’s aid society that are dealing with special needs children in your network, by any chance?

Ms. Kathleen Gifford: Well, we kept his foster parents. He luckily only had one foster parent. We tried networking a little bit with other family members—

Miss Monique Taylor: But I mean, like other families that have other children with special needs—did you stay in any of those kinds of networking groups?

Ms. Kathleen Gifford: No, I didn’t really know of any when we adopted him.

Miss Monique Taylor: Okay, it was just a curiosity that would have led me into another direction.

So when he turned 18, you lost \$10,000 for your Special Services at Home that you’re hoping you’ll get somewhere in the Passport world, I’m sure. It says, “July 2013 we lost \$12,000.” Where was that from? Was that from the children’s aid for the special needs?

Ms. Kathleen Gifford: That was from children’s aid. That was the subsidy, yes.

Miss Monique Taylor: It was brought to my attention earlier through this process—I believe that families who had children through children’s aid, and when those children aged out—children with special needs—they were then asked to move on and not keep those children anymore because they had aged out of the system. I had wondered if you had any contact with families who had been through that kind of situation, but you had adopted David so I guess that would have put you in a different position.

1610

Ms. Kathleen Gifford: Right. I have met families from this province who were at risk of losing their individualized funding. Thankfully, that hasn’t happened to David; I hope it never does. A friend of mine in Chatham, her son is the same age as Dave, the very same

capabilities, and he’s living in a psychiatric hospital right now.

I did want to point out that having real experiences around David, as opposed to getting him ready for real life—the self-injury that was so high in the classroom is less than six on a bad day. Most days, he’s functioning without self-injury. So there’s something to that whole programming aspect, that it’s just not good for people. People can’t thrive there.

The Chair (Mrs. Laura Albanese): Thank you.

From the Liberal side, are there any questions?

Ms. Mitzie Hunter: Thank you so much for sharing David’s story. I was curious to find out what was happening in his co-op program, because you were saying that it was such a good experience for him and he was learning new skills. Could you share a little bit more about that?

Ms. Kathleen Gifford: Yes. Some of the things—people didn’t think Dave was capable of learning around numbers and safety awareness. Basically, his 12-kilometre walk is six kilometres in the morning, he comes home for lunch, and then does another six in the afternoon. It is just walking through his community, going into and out of businesses, making purchases, learning how to use a bank, so anything that is going to help him learn for existing as an adult: things he couldn’t learn in the classroom, things that were attempted to be taught to him. Basically, it’s these journeys that he goes on. I didn’t know that he would understand the concept of money, and he has proven us wrong on that. The next step is teaching him value—so basically the academics of a classroom that he just couldn’t stop the self-injury enough to learn. He really needs to be on his feet.

Ms. Mitzie Hunter: Experiential learning.

Ms. Kathleen Gifford: Yes.

Ms. Mitzie Hunter: And you’re seeking to get that recognized as a course credit?

Ms. Kathleen Gifford: Definitely, yes. He’s 18 and legally needs to be in school until he’s 21, so that’s a big fear. I just don’t know what will happen if the option is to go back into a classroom.

The Chair (Mrs. Laura Albanese): Thank you very much for being here today and sharing your story with us.

Ms. DiNovo.

Ms. Cheri DiNovo: Madam Chair, another question of research that has come up, and thank you, research, for directing me to page 511 of the MCSS report. There it says 2,300 adults are on the wait-list. I have a couple of questions about that figure. If you compare that to the 4,500 residents with developmental disabilities who are currently living in long-term-care homes, clearly that figure is not being counted into the wait-list, the 4,500. That was one of our presenters who raised that before. So add another 4,500 to that 2,300, I assume, because I assume the first choice of parents is not long-term care for their children with developmental disabilities.

There’s that, and then—I haven’t totalled it up, but if I’ve got time on the flight tonight, I will—there seems to

be a real discrepancy in wait-list figures between the presenters here, if you add them all up, and the 2,300. Maybe somebody could add up those figures of the presenters here that actually have wait-list figures and the MCSS figures, because I suspect there is a discrepancy. It seems like way more from what we've heard from presenters, Community Living primarily.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you.

FASD-ELMO NETWORK

The Chair (Mrs. Laura Albanese): We'll go on to our next presenters, the Fetal Alcohol Spectrum Disorder network of Elgin, London, Middlesex and Oxford.

Good afternoon and welcome.

Ms. Juanita St. Croix: I'll just introduce myself and my colleagues here before we start. I am Juanita St. Croix. I am the co-chair of FASD-ELMO Network. I am also a facilitator with the Southern Network of Specialized Care. Directly to my right here is Angela Geddes, who is the assessment coordinator for our regional FASD assessment clinic, and on my far—this is my left; I'm sorry—left is Tracey Ashby, who is a public health nurse with the Middlesex-London Health Unit, and we are all members of the FASD-ELMO committee.

To start, we would like to thank the select committee for the opportunity to share information about fetal alcohol spectrum disorder and its impact on individuals, family and human services across the lifespan. We will be speaking from a regional needs assessment that was completed in 2010, published works on FASD and the FASD-ELMO Network's priority statement that was developed through consultation with parents and professionals in the region. We are providing copies of our full documentation for your review and consideration, as well.

Ms. Tracey Ashby: The FASD-ELMO Network is an unfounded, grassroots network of parents and professionals that was established in 2009 to raise awareness and improve practice related to FASD in the Thames Valley region. Current membership includes 57 parents and professionals from 23 groups and human service organizations in the area.

FASD is a permanent, largely preventable neurodevelopmental condition that impacts every aspect of life for individuals and families. Primary disabilities related to the physical impact of the teratogen—the alcohol—on a developing fetus can include neurodevelopmental damage, physical deformities and intellectual challenges.

The top three priorities for the FASD-ELMO Network are to promote and support interagency, inter-ministry and intergovernmental efforts in the areas of prevention, neurodevelopmental assessments and lifelong family-focused supports and interventions.

It was heartening to see a reference to FASD in MCYS Deputy Minister Alex Bezzina's presentation in October. Individuals who are affected by prenatal alcohol exposure face a lifetime of struggle, and are often missed

in service provision models because of a lack of diagnostic capacity and awareness.

Secondary disabilities are the disabilities that occur after birth, when there is a mismatch between the person and his or her environment. Early diagnosis and appropriate interventions can reduce the effect of lifelong deficiencies caused by this brain damage. These are some examples of secondary disabilities that can be lessened or eliminated through appropriate intervention: mental health problems, repeated school failures, trouble with the law, inappropriate sexual behaviour, and drug and alcohol problems.

The numbers related to FASD are daunting, and our capacity to serve individuals and families across systems requires education, collaboration and a change in paradigm. We know from our experiences in local capacity-building that this is not easy, but without a coordinated, systemic understanding, the loss of potential and the human devastation are unconscionable.

Ontario is behind other Canadian jurisdictions in identifying and serving FASD, but well-established models of identification and support in other provinces and territories are replicable and can be improved upon with a growing knowledge base. An FASD-informed approach, accurate assessments and appropriate services are important at any age.

In 2009, the cost of FASD annually to Canada of those from the day of birth to 53 years old was determined to be \$5.3 billion. From our experiences in the field, much of that is being spent on services and interventions that are not FASD-informed and lead to frustration and marginalization.

The importance of a systemic approach to prevention and harm reduction cannot be overstated. In spite of awareness campaigns, the rates of drinking have increased over the past 20 years. This increase was especially prominent among women and drinkers aged 18 to 29. It is from 1.3% in the year 2000 to 7.2% in 2009.

In just one study, and it talked about just one exposure—this was a 2013 study which showed widespread acute apoptotic death of cells in both grey- and white-matter regions of a monkey or macaque fetal brain, just from one exposure in the third trimester. Therefore, the importance of clear prevention messaging to prevent brain and neurodevelopmental damage cannot be overstated.

1620

Ms. Angela Geddes: Statistically, there would be more than 700 FASD-affected students in the Thames Valley District School Board alone, most of whom are not diagnosed or are misdiagnosed, leading to ineffective interventions or no interventions at all. Early diagnosis is critical in order to identify needs and necessary supports to assist students as they move through their education system.

Obviously, increased and dedicated funding is required to facilitate diagnosis. Staff and administrator education is also critical so that these students can access the education and support services that they deserve. This

education needs to be provided to all staff in all schools and all support workers, not just those who may have contact with an individual student.

Currently, 89% of children identified with FASD are in the care of agencies or are being raised by people other than their biological parents. This statistic speaks to both the hopes of families who welcome our community's children into their homes and the repeated disruption, which creates a further negative impact on the child's development. There is also the potential for this figure to hide the magnitude of the problem as there is significant mother blame, judgment and stigma currently when considering the diagnosis of FASD.

The estimated 1% of our population who suffer from FASD contribute to at least 60% of the prison population.

In a recent Alberta study, early diagnosis, a supportive environment and early intervention have been identified as crucial factors to optimize outcomes for affected individuals. The results of this 2006 Alberta study truly highlight the inappropriate cost and the importance of implementing positive structures and supports. Ontario needs to establish supportive interventions for transitional-age individuals and adults who are affected by FASD. We cannot assume that our incarceration rates, with our current lack of FASD-informed services and diagnoses, are any lower than those in Alberta.

Tragic stories of individuals who are impulsive, reactive, marginalized and who have committed random crimes are frequently reported in the news. Incarceration is a very costly and ineffective intervention for individuals who lack impulse control and cannot understand cause and effect. These are two primary impacts of prenatal exposure on the brain.

In London, we are fortunate to have a youth therapeutic court where youth who have committed a criminal offence and who have been diagnosed or suspected of having a mental health issue can be diverted from the usual criminal justice process. Dedicated cross-ministerial funding would ensure that these youth receive the support and services they require as they navigate our court system. We also know that not all youth who could qualify receive the therapeutic court services.

The current lack of understanding among practitioners places a great deal of pressure on the individual and the family. Family-focus supports and interventions, which are guided by a clear understanding of FASD and the strengths and the needs of the individual, as well as the abilities and needs of the caregivers, are urgently needed in a deliberate, coordinated approach over the lifespan.

Many adults who have FASD have either not been diagnosed or were incorrectly diagnosed as children. This leads to the development of secondary disabilities and tragic effects on their quality of life and life trajectories. Without appropriate dedicated supports, secondary disabilities associated with FASD can lead to high rates of mental health problems, including trouble with the law, confinement for treatment of the mental health issues or addictions, inappropriate sexual behaviour, homelessness, victimization, unplanned pregnancies, and

problems with employment. There are currently no specific adult diagnostic services in our region. Once transition from childhood to adulthood is complete, people with FASD cannot receive the appropriate supports and services to help them lead successful lives.

Ms. Juanita St. Croix: As the situation currently stands, the many kinds of service providers involved in supporting individuals with FASD and the level of the support provided demonstrate the complex nature of this disorder. But without designated funding specific to FASD, service providers are attaching funding from alternate sources in order to work with clients with an FASD. This results in fragmented delivery of services and supports that often do not meet the needs of the person.

Current service provision is costly and resource-intensive. There is an urgent need to increase supports across the lifespan, but also to target resource allocation further upstream in FASD prevention and support of affected children and youth to ameliorate resource allocation further downstream.

Current levels of service provision are not adequately addressing the needs of affected individuals. FASD requires a coordinated approach, with all service sectors working in a coordinated manner. When different sectors are not able to work with clients appropriately due to workloads, wait-lists, lack of funding etc., this impacts on the ability and effectiveness of other service providers. This is in addition to impacting outcomes for affected individuals and families.

A cross-ministerial approach to funding supports and services for a person with an FASD across a lifespan is needed to avoid the issues of transitions to adulthood, diversion when appropriate from the criminal justice system, and effective community mental health supports.

Planning for lifelong interdependent supports is also critical. The person may always need some level of supervision and support and multiple service provider involvement.

As previously indicated, there is a significant overrepresentation of FASD in the prison population. Court diversion programs such as the one in London's adult therapeutic court clinic are unique, given that there are varying levels of awareness of FASD within the judicial system in general.

However, FASD is not well understood, or is perceived as a non-issue for the judicial system, which leads to ongoing recidivism and punitive outcomes for a person with an FASD. Effective prevention of recidivism requires understanding FASD and supports and services tailored to the person's needs.

Caregivers of adult children with FASD express significant concerns for their affected children long-term with respect to planning for supports for care for their child when they are no longer able to do so, and the children's quality of life long-term.

Less than 10% of individuals who are diagnosed are able to live or work independently in adulthood, so supports based on functional ability are required for

success in all aspects of life, work and relationships. Because of a serious lack of diagnostic capacity in Ontario, often the level of support required is not recognized, and many affected individuals fail at behavioural attempts, which are contraindicated for FASD, to assist them and force them to levels of independence that are unrealistic for their functional ability. This results in the development of secondary disabilities.

The last point I would like to hit is not actually in a written statement. I would like to repeat the point that \$5.3 billion are already currently being spent federally annually across the lifespan to age 53. This resource allocation is not dedicated specifically to informed approaches and strategies around FASD and therefore is excessively costly and intensive. A cross-ministerial strategy acknowledging FASD strategies and supports is really recommended from a provincial level, which we currently do not have.

I just wanted to thank the committee for your time today and to open any questions that you might like to have.

The Chair (Mrs. Laura Albanese): And we want to thank you. We appreciate your presentation very much.

I believe it's the NDP's turn. Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much for your presentation. I'm just looking here: There's about one in 100 people in Canada—I know it's difficult because we don't have the diagnostic ability and people aren't getting diagnosed in Ontario, but do you have any idea of approximately how many folk are probably affected by FASD in Ontario?

Ms. Juanita St. Croix: In Ontario? We're probably looking at about 1% of the population of Ontario. If we can apply that same statistic, we're looking at about 1% of the population that we are aware of.

Ms. Cheri DiNovo: I was shocked to hear, for the first time, that OHIP doesn't cover diagnosis, and now I'm hearing that there are very few people who can do it anyway. So those are two very clear things that come through—to me, very obvious moves. What would be another obvious move that you would think that would be top of the list for this committee to go in the direction of?

Ms. Tracey Ashby: If you're looking at a prevention model—actually, in Edmonton in the fall, in September, there was the first international convention on the prevention of FASD. Many people from Ontario were there.

When we look at one of the key pieces of prevention, it is around screening and intervention, so looking at all primary practitioners, screening for problematic substance use, specific in this case to alcohol. If we did that—we know from research that a brief intervention, some motivational questioning, is enough to effect change in some of those women, to reduce the amount of alcohol, and, therefore, the incidence of FASD would be reduced.

1630

Ms. Cheri DiNovo: Now, a lot of that, of course, is in the schools as well, because we're talking about the first

few weeks, when women don't know they're pregnant as well.

Ms. Tracey Ashby: Exactly.

Ms. Cheri DiNovo: Binge-drinking behaviour—this was presented earlier—that kind of educational component. Thank you.

Ms. Juanita St. Croix: And I think, if we're looking at lifespan issues, if we look at the resources that are already spent—which I think is not a fact that is well known—funding is already going to services and supports. That is being misdirected. We think of a number of cases of parents of a child with an FASD who are in maybe five different mental health supports programs, where one would be quite effective and adequate if it were dedicated with an FASD strategy in mind.

I think the inter-ministerial piece is key, looking at it from the perspective of how we can look at what resources are already being spent and how we could streamline that with a directed strategy around FASD.

Ms. Angela Geddes: Again, with the FASD approach, I think that if we were better able to recognize it—some of the symptoms that we're seeing in the kids who are entering the school system, for example, or even going to our physicians—if we asked the question earlier about alcohol use prenatally, we would be able to assess more appropriately.

These kids are being seen by our system. They're seen at the school level. They're seen everywhere, but they're just not seen in a coordinated fashion that's FASD-specific. I think education and awareness throughout would be really helpful.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I think your group is not the first group today to talk about FASD.

I want to drill down. Ms. Ashby, you are a public health nurse. In your report here, you talked about the statistic of about 700 FASD-affected students at Thames Valley District School Board. How much resource or collaboration is there between the public health department and the school board? Can you share that with the committee?

Ms. Tracey Ashby: We are bound by Ontario public health standards. Within those standards it states, around healthy pregnancy, preconception issues. Our health unit has chosen, in this area, to devote time, as into FTE, public health nurses as well as some budget, to look at FASD. That is a choice of our health unit, though not mandated across the province.

We've been very fortunate to have that wisdom of our board of health. As well, Thames Valley District School Board has been very supportive of this issue around FASD and has been supportive of bringing together all our professionals for this network: bringing people together, looking at professional development and increasing awareness around that.

As far as the prevention piece, we have public health nurses who are in all the high schools, so there can be

work done if the teachers are agreeable to it and if it is within the curriculum to look at alcohol use during pregnancy.

One of our initiatives is also looking at college-level and university-level students and doing some initiatives around that, as far as mass-media campaigns around alcohol use.

Lots of movement is happening, though not mandated by any governmental body. It's the choice of what our health unit is doing.

Ms. Soo Wong: So can I ask a further question? Do I have time, Madam Chair?

The Chair (Mrs. Laura Albanese): One minute.

Ms. Soo Wong: One more minute. Quickly, is your health department the only health department putting dedicated resources to address FASD? Do you know of other health units?

Ms. Tracey Ashby: There are other health units that are putting money towards that, but again, it's not a set amount or a set expectation, so it would be depending on what priorities have been determined within those health units.

Nine of our health units in southwestern Ontario have gotten together and have put together an FASD poster and fact sheet to augment the Rethink Your Drinking campaign. That was around alcohol in generality. We saw that there was nothing with FASD involved. We pulled that together.

Again, it is not mandated. It is just the choice of the priorities of the health units. There are other health units that are working on this as well.

Ms. Soo Wong: Great. Thank you.

The Chair (Mrs. Laura Albanese): Okay, thank you. Ms. Elliott.

Mrs. Christine Elliott: I'd also like to thank you for your excellent presentation. One of the things that you focused on was the high percentage of people with FASD who get caught up in our criminal justice system. The adult therapeutic court that's here in London, I believe, is one of only very few in Ontario. I think there's one in Toronto and one in Ottawa, if I'm not mistaken. It sounds like you think it's a good concept, but maybe they're not specifically informed about issues around FASD to be as effective as they might be. Is that fair to say?

Ms. Juanita St. Croix: I think that's very fair to say. Without a mandate or some sort of a provincial strategy around it, it will not receive the attention that is required. It's still very poorly understood, regardless of efforts to educate the judicial system. There has to be interest.

Ms. Tracey Ashby: Through our local therapeutic court, we do have representation on our network around FASD. I think, of the ones that are in Ontario, we probably have a better view of that. We do have some lawyers who sit on the committee. We're getting that groundswell of information around this, and I think people are starting to see that this is an issue with people who are coming through, say, health or through developmental services. I think we're starting to build that knowledge base.

Ms. Angela Geddes: But without a diagnosis, it's difficult to determine for certain that it's not just a mental health issue.

Mrs. Christine Elliott: And it's a very different approach. With mental health issues, you can perhaps do more to work with people. With FASD, there is sort of a hard-wiring problem, so to speak, that makes provision of those services more difficult.

Ms. Juanita St. Croix: In other court systems that don't have a dedicated therapeutic court, they are looking very much for a concrete diagnosis to be able to do some diversion. There is diversion happening in other courts as well, just not a formalized service.

Thank you very much for your time.

The Chair (Mrs. Laura Albanese): Thank you, on behalf of all the members of our committee, for being with us.

MS. PATRICIA GALLIN

MS. DANA LOWRY

MS. WENDY RICHARDSON

The Chair (Mrs. Laura Albanese): We'll now call on the very last presenters of the day in London: Patricia Gallin, Dana Lowry and Wendy Richardson. Good afternoon. Please take your seats and make yourselves comfortable. When you're ready, you may begin.

Ms. Patricia Gallin: Thank you very much for this opportunity, and thank you very much for coming to London. It made things a lot easier.

My name is Patricia Gallin. While I am sure you have been hearing a broad range of concerns, I'm focusing on a very specific thing related to the recent transformation by MCSS of developmental services. My eldest son, John, is 28 years old, and has Asperger syndrome, an autism spectrum disorder; thus my involvement with developmental services over the past two decades.

Autism Ontario has already presented to the select committee, so you've heard about the unique challenges of ASD, and they've given you the broad picture. Our family is one of the thousands across Ontario that has been living with our own version of the challenges of ASD. Our son has a developmental disability. He has a social communication disorder that is going to challenge him for his whole life. He also has an IQ over 70.

John had to drop out of high school in grade 11, despite being in a special high school program for students with high-functioning autism. He was hospitalized for mental health concerns: depression, rage, self-injurious behaviour and suicidal issues—common complications of high-functioning autism.

During that time of crisis, John got some individualized funding; not a huge amount, but enough to make a big difference in his life. With that direct funding, we were able to customize John's support, since the few existing generic programs in our community weren't a fit. We hired people who worked well with him and his ever-evolving needs.

Over the last decade, with this ongoing support, John has regained his health, successfully gained his high school diploma and audited classes at both Western and Fanshawe. He has had some competitive employment and is working to gain future employment. John lived semi-independently with a roommate for two years but is back home until we can figure out something else in this climate of minimal residential support. He actively volunteers and is learning, in a more natural way, appropriate social communication with support staff who are his peers, even some who are female, which could not have been possible a few years ago.

1640

It's not perfect. This has been a slow and mostly progressive path. John is a contributing member to his community and, with more specialized supports, could likely contribute even more. With this support in place, even I have been able to finally work part-time outside of the home, though I remain the key person facilitating John's support and activities and worry about who will do this when I am gone—if only independent facilitation was an established option for families.

I'm telling you our story because right now, in 2014, I am thankful every single day that John is 28 years old and went through his hell when there was some support available. I fear for all of the families of teenagers with high-functioning autism today. Most will very likely be getting some form of support at school, only to be informed by DSO that at age 18 they will be ineligible for support. How is it that the very people with a social communication disorder, who, with just a small amount of individualized support, can make big gains, are now being discriminated against on the basis of IQ by the very act that is supposed to be promoting social inclusion?

One does not grow out of an autism spectrum disorder, and prevalence rates have only been increasing. Is this a convenient cost-cutting approach by MCSS? If there is no support from MCSS for these folks, where is it to come from? What in the world have we transformed the system into?

Ms. Wendy Richardson: My name is Wendy Richardson. We appreciate the opportunity to present to this select committee. My son Nathan is 27 years old, the third of four boys, and he has high-functioning autism. He does have an IQ above 70. He has an average to above-average intelligence but with many of the adaptive functioning deficits that people with this disorder suffer. He was not diagnosed until he was 13, even though I was telling the doctor I felt that he had autism.

In 2007, he suffered a complete mental breakdown as a result of circumstances at school related to a lack of understanding surrounding the disability. He was in a psychiatric ward here in London for two weeks. Because of this breakdown, he was not able to finish high school and did not receive his high school diploma. The doctors were not confident that he would recover and also told us that they did not know how to treat people with autism.

He did recover, and out of that crisis situation we received individualized funding that has allowed us to

create a somewhat meaningful life for Nathan. We have the help of support workers and various other supports paid for by this funding, which we are extremely thankful for. Without it, I believe that Nathan would either be in an institution of some sort or in some other horrendous situation and even possibly incarcerated, as he does have aggressive tendencies when he is anxious, stressed and fearful. This would cost the government far more than the small amount of funding that he receives, which allows him to contribute to the community rather than be a burden on it.

With the cueing and support of his workers, he is able to be in the community and now, because of their coaching, has been able to go out successfully on his own for short periods.

Nathan wants to live on his own and we would like to make that possible, given the right circumstances and environment. There is not any type of housing in London at present for this population. They do not do well in group homes, and also, the wait-list for those homes is 10 to 15 years. Those with an IQ over 70 are ineligible for service, so they would not qualify for this type of housing.

There is also a need for some type of meaningful work for this population. This would include having people who are educated in high-functioning autism and Asperger's who could do job coaching and job carving and be able to convince employers that having people from this population would be a valuable asset to their workforce.

There's a great deal of misunderstanding and lack of education surrounding the Asperger's and high-functioning area of the autism spectrum. This has led to the idea that if you have an IQ of 70 or over, you do not need any supports. This is simply not true, as this population has many and diverse areas of deficits. But with the proper supports and funding, they can be the functioning and contributing members of society that they want to be.

I will cite the example of a brilliant university professor who has Asperger's. He goes on speaking tours and must take a support person with him, as he does not like to be touched. His support person will make sure that people understand this and keep them from touching him, which could totally throw him into a meltdown. Also, when he is out of his regular environment, he cannot remember how to dress himself. Yet, this is a man who can speak to hundreds of people and teach high-level university courses without a problem.

In closing, I would like to say that if the ministry feels they spoke to families and were listening to their input, I would have to say they didn't listen very closely. I have been very involved with Autism Ontario for many years and also facilitate the parent support group. Not once have I heard a family say that people with an IQ over 70 do not need supports. Thank you.

Ms. Dana Lowry: My name is Dana Lowry and I am a sole-support single parent to a high-functioning adult on the autism spectrum. Thank you for your time.

My son Devon is 20 years old, in his last legally entitled year at high school, and was diagnosed when he was 18 during a three-year battle with severe anxiety. Poverty, mental health issues, social reclusiveness and a decreased access to education and employment are all issues that will plague him in the future unless we do something about it now.

I would like to talk to you about school, Developmental Services Ontario and some of the implications of the DSO.

On the subject of education, my son and I have had to fight for his legal entitlement for an education. My son's story includes him not attending his much-beloved school for three years while he hid in our house, missing his teachers and staff at the school and eating \$200 in groceries per week. His school was extremely happy to help him stay out, and when my son hit 19, his vice-principal talked him into signing documents to remove him from the registrar. It wasn't until they realized that we were going to the tribunal that the fight became a little less intense.

The exclusion of services that began in high school continued in earnest with the DSO once he hit 18. Because the DSO refused to accept any documents from his psychiatrist, I had to take him to a psychologist for an assessment—food for thought. The cost of an assessment is more than \$2,000. This is not refundable by most health care insurance providers. After we submitted our documents, we were told that my son “does not fall within the definition of developmental disability because his IQ is over 70%.” They referenced the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, section 3(1) to prove that he did not fit within this definition. But it is interesting to note that the act itself does not mention a specific percentile for cognitive ability.

The DSO has a chokehold on access to 18 out of the 21 relevant community services here in London. This kind of exclusion has disastrous ramifications for him and affects his charter rights. I struggled to find money to pay for much-needed services, and I know that there's so much more that he needs that I can't provide. Just a little bit of support would go so far for him: more time with his support worker, educational supports and social opportunities.

To conclude my presentation, I had mentioned at the start of my speech that poverty, mental health issues, social reclusiveness and decreased access to education and employment would haunt my son if we don't start to address the issues that face this population. As it stands, his future is bleak without support. It's not a lot of support—just a little bit could make the difference between being a hermit living beneath the poverty line and a successfully contributing member of society. I'm asking that you review the current state of the educational landscape for this population and modify the DSO's eligibility criteria to review the IQ and to recognize the adaptive functioning needs. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us. We have two and half minutes for each

party. I've lost track; I believe it's the Liberals. I'm going on good faith.

1650

Ms. Soo Wong: Thank you very much, Madam Chair. Thank you to each one of you for sharing your child's story with the committee.

I heard issues about the assessment, the DSO, the housing, the meaningful work—in terms of priorities, which one of these issues and challenges all of you experienced should be a priority for our committee?

Ms. Wendy Richardson: I'll address that. We talked about it beforehand and we would say, have them remove the criteria of the 70 points for the IQ. Then, other people who need this funding would have an opportunity to receive it.

Ms. Soo Wong: Okay, that's good. Thank you. Do I have more time?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Soo Wong: You talked about the challenges your son and you experienced dealing with the school board, in terms of not being in the school for a number of years. In terms of the accountability of the school board and their follow-up—for the three years that your son was not in school, which school board was it that didn't follow up? I'm just curious.

Ms. Dana Lowry: That would be the Thames Valley District School Board.

Ms. Soo Wong: Okay. During this period of time when your child wasn't in school, was there any call either from the principal, the area superintendent—

Ms. Dana Lowry: Every day.

Ms. Soo Wong: So what were the reasons for not drawing your son back into the school?

Ms. Dana Lowry: Their belief was that this was a behaviour issue and that punishment was the way to get him back to school. If it was uncomfortable for him not to attend school—so if he would be punished, threatened with suspension or expulsion—then maybe he would come to school.

Ms. Soo Wong: My last question is, what kind of support was provided to you, as the mother, so that he would be properly home-schooled, since he was not in school? What kind of support was given to you?

Ms. Dana Lowry: None. Home-schooling was never an option.

Ms. Soo Wong: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Jones.

Ms. Sylvia Jones: I'll try not to make this a rant. My first question is—and this number keeps changing—what percentage of the Ontario population has ASD?

Ms. Patricia Gallin: The prevalence is one in 94 right now.

Ms. Sylvia Jones: Okay. So, because of this magic eligibility 70 IQ, you guys aren't even on the waiting list?

Ms. Wendy Richardson: We were grandfathered in—

Ms. Sylvia Jones: Because of age.

Ms. Wendy Richardson: Yes, because of our children's age. But anyone, as of last April 1, who turned 18 after that date is not eligible if they have an IQ over 70.

Ms. Sylvia Jones: And it's your understanding that this is not by legislation; that this is some magic rule the DSO has implemented?

Ms. Dana Lowry: It's not listed within the act at all. There is no number listed in there. It's the DSO that has magically—my understanding, in attending a conference, was that the DSO and another entity had negotiated the 70.

Ms. Sylvia Jones: That's a heck of a way to keep the waiting lists down.

Mrs. Christine Elliott: Having served on the committee with Ms. Jones on the transformation of Bill 77, I specifically recall that we discussed that. We concluded that that 70 eligibility line was not appropriate; it was more a question of functionality that we should be considering. So this is something that we specifically tried to deal with with Bill 77 that somehow has come back at us.

Ms. Patricia Gallin: I went to all of those meetings and that's what kept coming up: that it should be adaptive functioning. But that's not what's happening.

Mrs. Christine Elliott: Thank you for letting us know about that.

The Chair (Mrs. Laura Albanese): Ms. Taylor?

Miss Monique Taylor: Thank you so much for your presentation today and for bringing this aspect to the table. Did I hear you say that your son wasn't diagnosed until 18?

Ms. Dana Lowry: Yes.

Miss Monique Taylor: What were the challenges that you faced throughout his life in trying to get that diagnosis?

Ms. Dana Lowry: We had multiple diagnoses ranging from, initially, a speech and language delay/communication disorder to, the latest and greatest before his final diagnosis with autism: schizophrenia. Most of these professionals were actually through the school board, because the wait time is less if you go through the school board.

Miss Monique Taylor: So, after struggling his entire life to finally get him a diagnosis, you're just being left in the cold because he has an IQ over 70? That's wonderful. That is absolutely horrifying, and the struggles obviously will continue. We've been hearing on a regular basis how people in that state are finding themselves in correctional facilities and places where they absolutely don't belong. I really hope that isn't the path that your son finds himself on.

All the best wishes for you. You were so lucky with the grandfathering and fighting those struggles through the years, so thank you again for being here.

Ms. Patricia Gallin: Thank you.

The Chair (Mrs. Laura Albanese): Thank you for appearing before the committee.

I want to thank, actually, everybody who came to present and to speak to us today here in the city of London. Thank you for the time that you have taken to be here. We usually say "for taking the time out of your busy schedule," but it's often an unpredictable schedule, as we heard very often today, so it's very much appreciated. It helps us to hopefully do a good job. That's what we're hoping for. Thank you.

I just wanted to say to the members of the committee as just a note, a parenthesis, that some of us are allergic to perfume, and today it's been a little bit challenging. We don't know whether it's that or it's the room, but if we as members of the committee could perhaps avoid wearing perfume or creams that are scented, that would help others out.

Interjection.

The Chair (Mrs. Laura Albanese): Yes, less use of Kleenex.

Mrs. Elliott?

Mrs. Christine Elliott: Madam Chair, if I could make one more request of research, just based on what we heard about the cut-off at 70 points for IQ: If we could find out how that came to be—whether it's by legislation, regulation, proclamation or whatever—I think we would like to get some more information on that.

The Chair (Mrs. Laura Albanese): Yes, I completely agree.

Ms. Wong?

Ms. Soo Wong: I was going to ask the same question as Mrs. Elliott.

Madam Chair, through you to the researcher: With respect to the school board issue, I also want to ask for more information from the Ministry of Education on how we deal with high-functioning autistic students. Given what we heard about one particular school board, I want to see data with respect to school withdrawal, home-schooling, expulsions and suspension of intellectually and developmentally disabled students in our system, because it's very, very disheartening for me as a member here to listen to a mother, a constituent in this area—that there was no support. So I want to know what happened and where the accountability is. I want to get more information about that, Madam Chair.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: I have a question for the researcher as well. There was a reference to a study in Alberta that looked at incarceration rates that were based on fetal alcohol spectrum disorder, and I wondered if there were any similar studies in Ontario and if those numbers could be made available to us.

The Chair (Mrs. Laura Albanese): Any further comments, questions?

We are therefore adjourned until 9 o'clock tomorrow morning in Thunder Bay.

The committee adjourned at 1659.

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CONTENTS

Monday 13 January 2014

Developmental services strategy	DS-221
Participation House Project (Durham Region).....	DS-221
Ms. Michelle Marshall	
Ms. Susan Buro Hamm	DS-224
Canadian Mental Health Association Waterloo Wellington Dufferin.....	DS-228
Ms. Adrienne Crowder	
Ms. Angela Allt	
Community Living Owen Sound and District; Community Living Walkerton and District	DS-232
Mr. Rick Hill	
Ms. Joanne Smithers	DS-235
Ms. Lynn Hainer	DS-238
Ms. Diane White	DS-241
Community Living St. Marys and Area	DS-244
Ms. Vickie Logan	
Mr. Harold Holland	
Registered Nurses' Association of Ontario	DS-247
Ms. Kathy Moreland Layte	
Ms. Sandra Mothersell; Ms. Jillian Mothersell	DS-251
Community Living Tillsonburg	DS-254
Mr. Urbain Demaiter	
Mr. Michael Kadey	
Mr. Marty Graf	
Ms. Mary Jo Winkler-Callighen.....	DS-256
Ms. Joyce Balaz	
Special Services at Home/Passport Coalition	DS-257
Ms. Susann Palmiere	
Ms. Joyce Balaz	DS-259
Mr. Bill Hiltz	DS-263
Mr. Arn Row	
Crossing All Bridges Learning Centre	DS-265
Ms. Debbie Brown	
Ms. Nancy Gowing	
Ms. Darlene Smith	DS-268
Community Living London.....	DS-272
Mr. Jim Hewett	
Mr. Murray Hamilton	
Ms. Michelle Palmer	
Ms. Kathleen Gifford	DS-276
FASD-ELMO Network.....	DS-279
Ms. Juanita St. Croix	
Ms. Tracey Ashby	
Ms. Angela Geddes	
Ms. Patricia Gallin; Ms. Dana Lowry; Ms. Wendy Richardson	DS-282



DS-11

DS-11

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Tuesday 14 January 2014

Journal des débats (Hansard)

Mardi 14 janvier 2014

**Select Committee on
Developmental Services**

**Comité spécial sur les
services aux personnes ayant
une déficience intellectuelle**

Developmental services strategy

**Stratégie de services
aux personnes ayant
une déficience intellectuelle**



Chair: Laura Albanese
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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON
DEVELOPMENTAL SERVICESCOMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Tuesday 14 January 2014

Mardi 14 janvier 2014

The committee met at 0901 in the Valhalla Inn, Thunder Bay.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning. The Select Committee on Developmental Services is now in session here in beautiful Thunder Bay. Welcome to all the committee members.

MS. CARRIE GROULX

The Chair (Mrs. Laura Albanese): I believe we have our first deputant already on the phone, Ms. Carrie Groulx.

Ms. Carrie Groulx: That's correct.

The Chair (Mrs. Laura Albanese): Good morning. I am Laura Albanese; I am the Chair of the committee. Where are you calling from?

Ms. Carrie Groulx: I'm calling from Ottawa.

The Chair (Mrs. Laura Albanese): You can begin your presentation. You will have up to 20 minutes to do so. If it is any shorter than that, that will allow time for questions from committee members. You may begin any time you feel ready.

Ms. Carrie Groulx: Thank you. Good morning, everyone. Thank you for all your combined efforts to make this committee happen. My name is Carrie Groulx; I'm a parent-advocate and currently have a postgraduate certificate in autism behavioural science with honours. The purpose of my presentation is to address the part of the committee's mandate to develop strategies and recommendations around the elementary and secondary school education needs of children and youth. Specifically, I will be discussing the effective use of educational assistants in Ontario schools and why the Ministry of Education needs to set standards for EAs—educational assistants—and force the school boards to follow Ministry of Education policies.

All of you should have a copy of the PowerPoint presentation. I'm happy to answer any questions at the end. On page 2 is my beautiful Melanie. I'll start on page 3 with Melanie's story.

Melanie was diagnosed two weeks before her second birthday. Devastated, as most, I panicked. I knew nothing about autism or what to do with her. Melanie was a flight

risk; sometimes aggressive; had pica, which is the ingestion of non-edible items; and tolerated very little. We went on a wait-list for services and were told early intervention was the key to her success. It was then I went back to school and received a postgraduate certificate in autism behavioural science.

Melanie received intense behavioural intervention, IBI, through the Autism Intervention Program. She received a secondary diagnosis of moderate mental retardation. Devastated but realistic, I concurred with her tardiness in learning—capable but tardy.

She then transitioned to the Ottawa Catholic School Board, where she was given an individual education plan, IEP, and a full-time educational assistant, EA. We saw some progress over the first five years of school and came across a variety of staff who were employed by the board, who sat in meetings and took notes but came up short on providing specific teaching strategies.

During this time, the ministry required them to use applied behavioural analysis, ABA, but they did not. Why, you might ask? I was told by my school board they do the minimum required by the ministry for special needs. The ministry has no standards for qualifications of an EA. The Ottawa Catholic School Board has no specific special qualifications required for an EA, and let's face it, the EAs are with the students most.

Despite my education and experience working with children using ABA strategies and my in-depth knowledge of Melanie, the school did not take any of the specific strategies I provided to achieve goals in her IEP.

On occasion, when one of the EAs in the schoolyard saw Melanie and me, they would witness something new. I would get Melanie to do something using ABA strategies we were working on at home. The response was amazing from the EAs. They would say, "Oh, wow. How did you get her to do that?" or "I didn't know she could do that." The EAs were thirsty for knowledge.

In September 2013, the start of the school year, she was assigned an EA who had been trained to use ABA strategies. The principal knew this would benefit Melanie and was thrilled to tell me. The team at the school was so excited, and I believe they were relieved to have someone with this experience. She was who we'd all been waiting for.

Six weeks into this fabulous year of achievement, this EA was declared surplus and had to leave. We saw more

progress in six weeks than we did in two years, so I decided to do what I could to get her to come back.

EA assignment, slide 4: The Ottawa Catholic School Board groups all special-needs students into one category and hires EA staff as generalists, requiring no specific skill set for the special needs of the children they work with. How could this be? Why shouldn't EAs be hired to work with specific groups of students and required to have specific training? Because they don't have to.

On November 13, Miss Monique Taylor told the committee—and if I may, I'll quote from the transcript, page DS-41—"My concern and what I'm hearing from many parents is that there's no consistency with their EAs." Well, Miss Taylor, that's true. Not only are some children sharing EAs when they need full-time ones, but EAs get yanked, even if they have special qualifications that meet the needs of the children they were assigned to help.

I quote Mr. Clarke, on page DS-42: "About \$11 million a year is provided to school boards particularly for training around applied behaviour analysis so that there are people who have a more advanced understanding of how to support teachers in the principles of applied behaviour analysis and that those classroom teachers can, in fact, be supportive of those children." This is very disturbing. Mr. Clarke is saying there's \$11 million a year to have a more advanced understanding. Where is the EA, the one who is one-on-one with the students in that \$11 million?

I contacted the board where my daughter's first EA was originally trained. They told me that they provide training to the staff two weeks into the school year for those who work with children with ASD, autism spectrum disorder. They let me know that the Geneva Centre offered free online courses. I told my superintendent of special needs what I had learned. I know from this forum that the Ministry of Education gives the Geneva Centre money annually, so it's not really free but is widely available for those who know about it. I was told by my superintendent of special needs that they needed money to provide EAs with the time off to get trained—no mention of giving them this information or suggesting professional development days would be dedicated to this.

There has to be an incentive for educational assistants. They're often the lowest-paid employees at the board. The EAs who work with the students with ASD are the ones who need the ABA training. They deal with constant opportunities all day long to provide strategies if they have the knowledge.

One of Melanie's teachers received two-day training in ABA in the past. None of the goals in her IEP were ever executed using specific ABA strategies outlined in policy/program memorandum 140, PPM 140.

Perhaps this money could be better spent training EAs who spend more time away from the classroom and away from a teacher, in the resource room, recess, assemblies, in our board church, body breaks, news shows, and outings such as track and field and Special Olympics.

The Ottawa Catholic School Board's reassignment of EAs is based on seniority, with a clause in the current union contract agreement—page 24, section 2, "Surplus to School: Where there is a reduction in the total education assistants positions in the school, education assistants will be declared surplus, subject to 'special qualifications' (e.g. Braille, ASL)"—American Sign Language—"based on FTE"—full-time employment—"status and seniority date as per article 18."

Even though there's a clause in the current union contract, the Ottawa Catholic School Board does not acknowledge ABA as a special qualification. They don't have to because the ministry doesn't force them to. They do say they acknowledge ABA as a scientifically proven way to teach these children. Unfortunately, they lack the qualified, trained staff to implement student-specific strategies. I've seen this first-hand.

0910

Slide 5, ABA in the classroom: The Ministry of Education issued PPM 140 in 2007. It states, "School boards must offer students with ASD special education programs and services, including, where appropriate, special education." "Principals are required to ensure that ABA methods are incorporated into the IEP of students ... where appropriate."

PPM 140 provides, under "Principles of ABA Programming," that some students may require more intense programming. Let's stop and take a look here. Your committee is looking for recommendations with respect to the urgent need for comprehensive development strategies. The Ministry of Education's strategy as of now is, they have PPM 140 and \$11 million spent. The problem lies with no "standard of qualifications" from the Ministry of Education—therefore, not at the board level—for special qualifications of an EA. That means an EA requires no skill set to work one-on-one with special-needs students, and let's throw in not training them so they are not set up to succeed.

PPM 140 came out with a resource guide entitled *Effective Educational Practices for Students with Autism Spectrum Disorders*, which has been proven to provide information but not the how-to teaching using ABA strategies. This is what the ministry gave them to support children on the spectrum.

On page 176 of the guide, there's an ABC data sheet: just the sheet; no explanation on how to use it or what to do with the information collected. What it does show, on the next page, is a list of examples of what to teach. One of them is "I want." Unfortunately, it does not provide specific ABA strategies on how to teach the "I want," instead of a behaviour like biting. This key element is missing from the ministry-published guide on how to teach the "I want."

The principal consulted me the first week of school on what to do about a problem behaviour with my daughter. I gave her a specific ABA strategy and told her to do exactly what I said and exactly how I told her to do it. She did, and the behaviour disappeared immediately. How powerful.

It's easy to get them to listen to me or anyone when it comes to problem behaviour, but when it came to consulting on an ABA strategy in order to help her to achieve her goals in her IEP when it came to education, it has been a real challenge.

My daughter bit her new EA in a "moment of silence" on November 11 because a well-known trigger was present. The well-known trigger was in her file somewhere for the last five years. She was away from her teacher who had had that two-day training in ABA. She was rewarded for this behaviour by getting to leave the gym. The reinforcement of this bad behaviour is now learned: All she has to do is bite and she gets to leave.

We have to stop this by using ABA strategies to teach functional communication training, the "I want"—"I want to leave" or "I want to go"—instead of biting. The EA spends more time with that child than anyone else. Shouldn't she be trained to succeed instead of being set up to fail?

Educators know that not all children learn the same. Children on the spectrum, we do know, benefit from using ABA strategies. The opportunity we have to make a difference is right now. The children in our school system are there for 16 years. We can do it right, teach them how to ask for something, or teach them that biting gets exactly what they want effectively and immediately.

From DS-195, Mr. Steve Levac from the Peel Children's Aid Society—and I only quote parts of what he said because I'm short for time—just to reiterate the point that so many people are looking for the answer and it's right here: "We need to figure out what help our education sector needs to be able to provide safe and practical education to special-needs children and to children with developmental disabilities." This is a real challenge.

The benefits of ABA is slide 6. For more than 30 years, ABA strategies have been scientifically proven to teach autistic children appropriate behaviour when it comes to their triad of impairment: socialization, communication and behaviour. The Ministry of Education recognizes and requires the use of ABA, but they do not tell the school boards how to spend their money and who to train. ABA strategies are simple and provide a step-by-step instruction on how to teach a specific skill.

ABA reinforces positive behaviour. For example, I used an ABA strategy to teach my daughter to count six squares of toilet paper so that she would stop flooding the toilet. This was a terrible problem causing damage and extensive cleanup. Having this skill will benefit her for her entire life, several times a day, everywhere she goes, even after I'm gone. Using these scientifically proven ways to teach, they are learned. The applied behaviour steps help children reach their potential, diagnosis or not.

Teaching children skills using ABA when they're young provides them with a lifetime of tools that contribute to being better integrated into schools and community where we all live. Each child can reach their full potential. It would be cost-efficient and more effective to train EAs to use ABA, even giving them time

off instead of paying higher-paid people who are not one on one with the students.

Slide 7, this is the conclusion: We all recognize that early intervention is the key to a child's success. Funded by the Ministry of Community and Social Services, the autism program is in place. Great, if you can get it, but it's only for two or three years. Then you transition to the next step, leaving behind trained staff and a curriculum essential for success.

The next step is the school system. This is so critical to a child's ongoing success. It's a 16-year opportunity. All children get to go to school, and it's funded by the Ministry of Education. We have principals, teachers, resource teachers and EAs in the schools constantly and every day. Then there are the specialized people: autism spectrum disorder consultants—ASD consultants—speech and language pathologists, behaviour consultants, itinerant resource teachers, school psychologists and occupational therapists. They consult, often leaving a report behind that ends up in a file in a filing cabinet in an office, nowhere near an EA who can refer to it. This system is expensive and not utilized to its potential.

I've seen first-hand how an ASD consultant was unable to provide a specific ABA strategy and used verbal prompts, which are the hardest to fade, when asked to contribute. This is where part of that \$11 million is going? Oh my, we have a serious problem.

Get all the EAs trained to use ABA strategies that work with children so that in the 16 years we can see an increase in skill acquisition. Properly trained EAs could prevent, for example, a behaviour consultation by not reinforcing bad behaviour, like rewarding a child when they bite by removing them from an undesirable situation. This is why we have young adults with ASD leaving the Ministry of Education and ending up no further ahead after 16 years because they didn't have properly trained EAs using principles of ABA.

We can serve these children better by having funds put into the training of front-line workers. They would work with the highest number of special needs children entering the school system today. The cost of lost opportunity is beyond my comprehension.

The public board plumbers in Ottawa are changing all the toilets in the special needs' classrooms because they're getting plugged up and flooding. Use a simple ABA strategy, as I did with my daughter, and they wouldn't have to solve this situation with a band-aid solution. They would take this opportunity and turn it into a lifelong learning opportunity. All it takes is for the EAs to be trained using ABA strategies.

Autism isn't going away. We can't ignore the fact that there is a scientifically proven way to teach these children, and we have 16 years to do so. ABA training is clearly not reaching all the EAs who are providing support to children with ASD. The Ministry of Education strategy on how to deal with this is not working.

What has happened to that \$11-million annual investment? It may be with those specialized staff who left the report in a file at the school. It is definitely not with the

EAs working with a child on the autism spectrum who could benefit from ABA. In five years, I've not seen any benefit to this \$11 million.

One thing I know for sure is that the EAs are the ones with the kids the most. We have a 16-year opportunity; we need EAs trained to use ABA strategies to make the most of this time.

The Ministry of Education needs to set standards for EAs and force the boards to follow the ministry guidelines. The Ontario government, over a lifetime of a person with autism, will pay for them through several different ministries. The opportunity to have educators and one-on-one support is during those 16 years. It's time for a change to get first-hand knowledge of ABA to the EAs who are the front-line workers. They're not going to let that knowledge sit in a file; they will use it all day long.

I thank you for this opportunity to be able to discuss with you the essential use of ABA strategies by properly trained EAs for the development of lifelong skills for children with autism spectrum disorders. I tell everyone, "It's behavioural science, not rocket science. You can do it; you just need to know how."

Thank you for investing in the future. Oh yes, the children thank you also.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. We have less than a minute for each party to ask a question, so maybe just a comment on that. Ms. Elliott?

0920

Mrs. Christine Elliott: Well, thank you very much, Ms. Groulx, for your presentation today. I entirely agree with you that we do need training for EAs working with students and the ABA principles. Though I don't know that much about them, I do know that they're very effective teaching tools, and you've really illustrated that very well today. We will certainly take that into consideration. Thank you very much again for joining us.

The Chair (Mrs. Laura Albanese): Ms. Taylor?

Miss Monique Taylor: Hi. Good morning, Ms. Groulx. Thank you so much for joining us. You're absolutely right. You brought a very important piece to this table in speaking about PPM 140. I know that that will be a conversation going forward here and something that seriously needs to be looked at. Thank you so much for everything that you're doing and for bringing this to the table this morning.

Ms. Carrie Groulx: Well, I just wanted to make sure that you guys were aware that the ministry does not make school boards implement anything. Mr. Clark talked about giving the school boards money, but they don't have any say in what they do with that money. By not enforcing any policies, the school boards can do what they want with that money. Right now, because the standards are so low for hiring EAs, when I tried to get my daughter's EA back because we had sought more progress, we weren't able to do so because they don't require them to have specific qualifications. It didn't make sense. It needs to change.

The Chair (Mrs. Laura Albanese): I have Ms. Hunter who wants to make a final comment.

Ms. Mitzie Hunter: Thank you very much for sharing Melanie's story with us this morning. I'm just noting here that you've given us some advice, such as needing to ensure that all of the good work that is being done with students doesn't just sit in files, that it's actually brought into the classroom and is applied. I think that that's something that we can certainly take back. We share your sentiment that no skill set that is being utilized should go unused, and should be for the success of our children in our classroom. I want to thank you for sharing Melanie's story.

Ms. Carrie Groulx: You're welcome. I think that it's an important key to understand that the front-line workers, the ones that are with them all the time, that know them the best, are the ones that need to be trained, and it's not happening, because the board doesn't have to, because the ministry doesn't make them. If the Ministry of Education has this wonderful strategy and the PPM 140 in place—it's not happening. I've been in the school board for almost six years now, and I have not seen any of it. It was through my efforts in finding out how I could get that specifically trained EA back that I came across all this information. So it's very new knowledge to me, and I'm taking it as far as I can to make sure my daughter and everybody else who is in the system has that same opportunity. Sixteen years of one-on-one in educators, and we can't do better than this?

The Chair (Mrs. Laura Albanese): Thank you, Ms. Groulx. We really will take your suggestions into consideration here at the committee.

Ms. Carrie Groulx: Very good.

The Chair (Mrs. Laura Albanese): We really thank you for presenting to us this morning. We'll have to move on to the next presenter. We're on a very tight timeline.

Ms. Carrie Groulx: Absolutely. Thank you for your time. I appreciate you listening and understanding the need in this particular situation. Good luck.

The Chair (Mrs. Laura Albanese): Thank you.

MR. GREG BONNAH

The Chair (Mrs. Laura Albanese): We'll now move on to Mr. Greg Bonnah.

Mr. Greg Bonnah: Yes.

The Chair (Mrs. Laura Albanese): Good morning.

Mr. Greg Bonnah: Good morning.

The Chair (Mrs. Laura Albanese): Where are you calling from?

Mr. Greg Bonnah: Ottawa.

The Chair (Mrs. Laura Albanese): Ottawa. The committee members are all here and we are eager to hear your deputation. Please go ahead.

Mr. Greg Bonnah: Okay. Good morning. The subject being covered today is one that I've advocated for years. However, before this laudable goal has a chance of realization, you will have to make the individual minis-

tries accountable for what they do right now. Let me clarify this with a personal account of how, currently, the individual ministries do the minimum until the person with the disability is another ministry's problem.

The Ontario Ministry of Health knows that one child in 50,000 will suffer what they call an adverse event to their vaccines. In 1986, MPP Cam Jackson introduced a bill that would have mandated the ministry to test all children who suffered a reaction to their first vaccination. This bill was defeated, so in 1991 we were compelled by law to sacrifice our child.

His adverse event was Lennox-Gastaut syndrome. His brain was seizing every four seconds, and we were seeing between 60 and 100 myoclonic and/or atonic "drop attack" seizures per day. My research indicated that 70% of the children with this syndrome die within the first year and that if he had the misfortune to survive, he would be a vegetable.

The experts at the Children's Hospital of Eastern Ontario confirmed this by indicating that our child would never walk or talk, and advised us to give up our child—at a cost to the Ministry of Community and Social Services in 1991 of \$250,000 per year—and get on with our lives.

From my perspective, the costs involved in taking care of the few children harmed by the vaccines far outweigh the costs to the Ministry of Health for testing all children for adverse events, but to this day, they continue to refuse to do that because of the costs involved to their ministries. This, in my view, is a perfect example of how, currently, the individual ministries do the minimum until the person with the disability is another ministry's problem.

Now on to the Ministry of Education: Despite what section 8(3) of the Education Act states about the minister ensuring that exceptional children will have the appropriate special education programming, and services without payment, in 2003 I was required to spend \$40,000 of my own money, for which I've never been compensated, and forced to go to the Ontario Court of Appeal in order to have my child educated.

Until that time, special education students were not considered to be "persons" under the Education Act, which thereby allowed school boards such as the Ottawa-Carleton District School Board to legally place special education students in non-academic environments and do the minimum for them until they were another ministry's problem.

Unfortunately, making special education students "persons" under the Education Act did nothing for students who were labelled as developmentally delayed or mildly intellectually delayed, because the Education Act, in its regulations, still states that they have "an inability to profit educationally within a regular class because of slow intellectual development." My child has demonstrably proven this declaration to be false, because his IQ, as determined by the OCDSB's expert witness, their psychologist, at his education tribunal was reported to be at the 0.01 percentile.

Nonetheless, in the six years that the OCDSB chose to obey the court order and provide him with the resources required to access the curriculum, he successfully completed the grade 3 EQAO testing.

Imagine where, academically, my child would be today, had the OCDSB chosen to save the million taxpayer dollars that they squandered in their inane attempt to maintain the status quo, and had provided him with the resources required to access the curriculum for the full 15 years that the Education Act, in its regulations, says he was entitled to.

Finally, from my perspective, the Ministry of Community and Social Services is the textbook example of homeostasis. The government of Ontario, in Auton, stated that they would take care of any person that they knowingly harmed, yet here in Ottawa, this ministry has a one-size-fits-all policy. This ministry is quite willing to pay hundreds of thousands of dollars a year to segregate a person who has a developmental disability, but they are unwilling to provide the resources necessary for them to reach their full potential in the regular environment.

I have written countless times to the Premier, inquiring as to whether the bureaucrats were there to meet my child's needs or whether he was there to guarantee a few bureaucrats lifetime employment. For reasons that I am unable to fathom, the Premier and her predecessor have refused to answer this simple question.

I could go on endlessly with the difficulties I've encountered with this ministry, but I have a limited amount of time.

So, to conclude, if the government of Ontario had been thinking of my child as a whole instead of just components of what its individual ministries were allegedly mandated to do, then my child would not have been incapacitated or, at the very least, would have had the opportunity to reach his full potential in a regular environment.

Until the government of Ontario makes the individual ministries accountable for what they purportedly do, then they will continue to do the minimum for persons with developmental disabilities until these unfortunate souls are another ministry's problem.

Thank you.

The Chair (Mrs. Laura Albanese): We thank you for your presentation. We have about four and a half minutes for each party for questions, so I would ask Ms. DiNovo or Miss Taylor to begin. Miss Taylor.

0930

Miss Monique Taylor: Thank you very much, Mr. Bannah, for being here with us this morning. We really appreciate your time. You've brought up some interesting topics. Something that we've definitely been focusing on and hearing from many presenters is the fact that we need to have one ministry taking care of people with developmental disabilities, because crossing ministries makes things confusing, makes things harder for families, and it's so important that we get things under one umbrella.

Mr. Greg Bannah: I agree and disagree with you, because the Ministry of Community and Social Services

recently rolled out Developmental Services Ontario, which is supposed to be one-stop shopping. But we're finding, those of us who want inclusion here in Ottawa, that we're just put on waiting lists and nothing's being done, while the segregationists are getting everything. So one ministry is great, but it's all going to be in the details on how it's rolled out.

Miss Monique Taylor: You're absolutely correct, and wait-lists are definitely something that we're hearing about more than often. We all know that that's the reality of what's happening right now and it's not acceptable. We need to make sure that we have smooth transitions for families to be able to deal with their daily lives.

Mr. Greg Bonnah: Yes.

The Chair (Mrs. Laura Albanese): Thank you. I will now move on to the government side. Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you, Mr. Bonnah, for joining us at the hearing today and for sharing the experiences that you've had. We've certainly noted those concerns. I have, in particular, noted that we cannot expect that we would do the minimum for students with special needs by having them participate in non-academic settings. I think that we have to ensure that the curriculum is being applied to the fullest possible potential and—

Mr. Greg Bonnah: Then explain to me how come there are six schools for developmental disability left in Ontario? I think it's McCordic in Toronto, one in Thunder Bay where you are, and the other four are here in eastern Ontario.

Ms. Mitzie Hunter: Yes, and I think that's what the purpose of these hearings is. It's to hear all sides and a range of issues and concerns. We've certainly heard from some of the presenters that they see value and benefit in some of those specialized settings, and others far prefer the integrated classrooms. I think that we're listening and ensuring that we take in the feedback and the input from all sides, as the focus of our report is to look at how do we address the needs of children and youth and adults in Ontario with intellectual disabilities and those who are dually diagnosed, as well, and how do we coordinate the delivery of developmental programs and services across many provincial ministries in addition to the Ministry of Community and Social Services, so that—

Mr. Greg Bonnah: Well, my child has proven that with the right resources, you can go places. The OCDSB stopped educating him once he successfully completed grade 3 EQAO testing because they don't want people to know that these kids can go far.

Ms. Mitzie Hunter: Yes, and I think that's why we're here, to actually ensure that these children and adults do go far and really achieve their goals and their aspirations, so thank you.

The Chair (Mrs. Laura Albanese): Thank you, and I will now turn it over to Ms. Jones.

Ms. Sylvia Jones: Thank you for your presentation, Greg. You are not the first parent who has talked about the frustration between transitions from various ministries, so I want you to be assured that your voice is not

alone. We're hearing it consistently province-wide, and I'm sure it's one of the many things that we will try to grapple with as we prepare our recommendations. So thanks for your input.

Mr. Greg Bonnah: Well, I was hoping that I could speak to you on Friday when you are here in Ottawa, but again, the selection committee decided who they were going to allow to speak and not speak, so I'm thankful that you guys allowed me to speak to you today.

Ms. Sylvia Jones: Not a problem. As you can imagine, there are many, many families and individuals who are passionate about this issue, and we're very thankful that they're taking the time to put together the presentations.

Mr. Greg Bonnah: Okay.

The Chair (Mrs. Laura Albanese): Yes, we had many people who wanted to speak to us in Ottawa, but there were difficult decisions to make; it was hard to accommodate everybody. We welcome the opportunity to speak to you via teleconference today.

Thank you very much for your presentation. It was really helpful to the committee, and we will take your suggestions going forward.

Mr. Greg Bonnah: Thank you very much.

The Chair (Mrs. Laura Albanese): Have a great day.

MS. HELEN LEASK

The Chair (Mrs. Laura Albanese): We will now move on to our next presenter, Ms. Helen Leask. Hello?

Ms. Helen Leask: Yes, hello. I'm here.

The Chair (Mrs. Laura Albanese): Hello. Good morning. This is Laura Albanese; I'm the Chair of the committee. How are you today?

Ms. Helen Leask: Pretty good, although I will have a bit of a scratchy throat in my presentation, for which I apologize.

The Chair (Mrs. Laura Albanese): That's no problem. Where are you calling us from?

Ms. Helen Leask: I'm calling you from downtown Toronto.

The Chair (Mrs. Laura Albanese): Okay. I guess you're enjoying probably warmer weather compared to us here in Thunder Bay, but it's a nice day here as well.

I would ask that you start your presentation by stating your name and what you do. You will have up to 20 minutes to present. If the presentation is any shorter, that will leave some time for questions from the committee members. You may start any time.

Ms. Helen Leask: Thank you, yes. I understand. Because I have virus brain, I've written all this down. Please bear with me as I go through it.

Members of the select committee and Ms. Albanese, thank you very much for inviting me. I will give you a bit of detail about myself before I start, if I may. Actually, I should just let you know there was a bit of an echo going on—I think somebody got rid of it; that's great.

I was a science researcher and then a science journalist in the UK, but for the last 15 years I've been the partner

in a medical communications company here in Toronto. I actually spend my time facilitating groups of top doctors to figure out how to improve the health care system, so let's just say I do understand a little bit about trying to fix complex systems.

However, of course, today I'll be using my 15 minutes to share some personal experiences, in this case with developmental services, and also some of the conclusions that I've drawn from these experiences. I realize that you'll be hearing from many people and all of us hold a different piece of the puzzle. My piece involves the care of developmentally delayed folks with complex medical needs: in short, my 22-year-old daughter.

I don't have to tell you that developmental delay is a challenge by itself. If you add into that difficult behaviours, you have another layer. Turn up the heat a little and add psychosis, delusions and violence, and then add to that life-threatening seizures, and for a single self-employed parent, this is a torpedo through everything: your family, your other children, your financial stability, your business relationships—everything. You're in survival mode for years and years and years.

Let's start in the proper place, with my daughter. As this is a public record, I've glossed over some of the details for her protection, but I have included some because I think it's in the details that we're going to understand all this.

My daughter was born apparently normal; her developmental delay first appeared as a slight learning difficulty in kindergarten. By nine, she started having seizures, and by the age of 11 she was classified as having intellectual disability.

Her cognitive abilities actually went backwards throughout her teenage years. She seemed to forget everything she learned as fast as she learned it. Our bright little daughter gradually disappeared. From a five-year-old who spoke like a BBC announcer, now, at 22, she can barely form a complete sentence.

We now know that she has a rare genetic disease that affects how the brain forms its neural connections. As her brain grew, it simply got more and more chaotic.

High school was a huge challenge with increasing behavioural problems. She went to a public school here in Toronto for developmentally delayed girls which should have been absolutely perfect. Unfortunately, she hated it. She was bullied incessantly. She learned to fight and to swear and be violent and abusive. On one occasion, a group of girls tried to set her on fire, and the staff did nothing. Not surprisingly, she started to refuse to go to school. This was a logistical nightmare.

I heard other parents complain about PA days. Well, we endured 18 months of school refusal—off again, on again, off again, on again. I didn't dare leave her all day because of her seizures, so it created huge practical difficulties.

0940

I was a single, self-employed parent who had just started working outside the home. I definitely couldn't afford full-time child care, but I paid for it anyway.

In the end, my family helped out, and we found a private school that specialized in brain-injured children, and her attendance gradually increased. Then the behaviour started to come back, so we had aggression, repetitive speech, frustration, separation anxiety, you name it. It's impossible to describe what it's like living with such an individual. Let's just say, try to run a business when your anxious child is calling you 10 times an hour.

In 2011, a series of seizures over 24 hours led to several days in intensive care. When she emerged, her brain was deeply injured and she became even more difficult to manage. Two months later, she was admitted to the Sunnybrook psych ward with psychosis. At this point, I first made contact with developmental services. It was clear that the world had changed permanently. This was no longer curable with camps and special schools and counsellors. As her mother, I could no longer save my daughter if I just tried a little harder. This was deep, enduring and very, very complex. We were scared for her and scared of her.

The first thing that struck me about developmental services was how kind everyone was. I was so used to battling through on my own that it was a shock to be offered a helping hand and be told, "It's okay to feel like this. It's normal." However, it was rapidly obvious that all these kind people were doing their best despite the system, not because of it.

There was a huge amount of duplication. Each agency had its own forms in triplicate, all filled out laboriously by hand. One case manager confided to me that she stayed at home one week in four just to get through the paperwork. They all asked the same questions, needed the same medical and psychological forms signed and the same permissions. They all had to visit me and my daughter several times. This was very comforting, but what a cost to the system. Surely they could all work off the same software, I thought. How much are laptops these days—\$400, \$500? That's much cheaper than a case manager staying home one week in four. And couldn't they all pool their intake system and send just one or two people on a preplanned assessment schedule and circulate the results?

The next thing that struck me was how little actual cash there was for services—for respite, for day programs, for residential care, even in a crisis situation. On a bad day, it seemed as though all the money was going on the army of interviewers and mountains of forms and that there was none left over for actual services.

The funding became most acute during our numerous crises. For example, one day our caregiver quit on the spot because my daughter pushed her head into the floor again. Both myself and my ex-husband were working full-time. We could take a few days off but no more—remembering this is a 22-year-old adult we're talking about, not a child. Even if we could have found someone on short notice, there was no way a regular caregiver could cope. It needed somebody with specialized skills. We applied for crisis funding as a short-term band-aid, to be told there was no further funding until April, which

was three months away. So we were left with a violent, seizure-prone, developmentally delayed young woman with no one to care for her. In the end, all we could afford was a specialized agency caregiver in the afternoons, and we had to keep our fingers crossed in the mornings.

The point of sharing this story with the committee is to illustrate what can happen when a person with developmental delay is medically complex—in this case, has life-threatening seizures and mental illness. She needed 24-hour care because of her seizures, but in this case, because she was also violent and needed expensive specialized care, which we couldn't afford, we had to risk her life by leaving her unattended.

This kind of scenario also means that we've had frequent interactions with the health care system and with the police. When there's no crisis funding, we're told to dial 911 if she gets violent. Needless to say, these are extremely hazardous and complicated experiences. On one occasion, after she had attacked me, the police asked me if I wanted them to arrest her—a question no parent ever should be asked. I couldn't bear to imagine the danger this would put her in, this medically frail young girl, so I told them I could manage. We all remember Ashley Smith. In effect, I had to choose between the safety of myself and the safety of my daughter.

The emergency room is little better. Both times my daughter was admitted to the psychiatric ward, my ex-husband and I had to battle for hours and hours to get her in. Both times they told us that the psych ward couldn't admit her because of her seizures and the neurology ward couldn't admit her because of her psychiatric symptoms. So a tertiary level teaching hospital couldn't cope with someone like my daughter, but the families could—or the families were supposed to, I should say.

While encounters with the emergency services are always bruising and discouraging, the long-term prospects seem even bleaker. Thanks to the efforts of our case manager, last year my daughter came up twice for a residential place. In both cases, they turned her down in the end, saying they couldn't meet her needs. Surely there has to be a better way of caring for people as complex as my daughter.

In the end, we simply couldn't cope with her anymore and I decided not to wait for the system. Last summer, I sold my house and used the proceeds to move my daughter into a small condo with a full-time caregiver. This was expensive and complicated but has been astonishingly successful. Although she's still very unwell, my daughter now is in a much better mental state with her new-found independence. She is well integrated into the community and has just started a full-time job in a sheltered workshop. Needless to say, the rest of her family are also in a much better mental state.

I realize many families are not in a position to move their child out like this, but I would ask the committee to consider how they can help families that are thinking about it. I don't have to tell this committee that caring for my daughter in the justice system, a group home or the

mental health system would cost upwards of \$200,000 a year. Caring for her in her own condo costs one fifth of that: \$45,000 a year. Unfortunately, there's no official funding for this kind of arrangement.

I would strongly urge the committee to consider better ways of providing more support for families like us who are thinking of making their own residential arrangements for their children, perhaps by direct funding for caregiver costs or as a tax break on all disability-related expenses. Most families want to help their own children. This, I believe, is a great use of taxpayer dollars for these complicated, vulnerable people and provides a much better quality of life for them than the prisons, the homeless shelters and the psychiatric wards of this province.

I hope that my experiences are helpful to the committee and to all special families in Ontario. Thank you for listening.

The Chair (Mrs. Laura Albanese): Thank you very much for illustrating so well the situation you had found yourself in and for your suggestions to the committee, which we find very valuable. We have about two minutes for each party to ask questions. We will start with the government side, Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair.

Thank you so much for sharing your experiences. I wonder if you could expand on your daughter's experience in the full-time job that she has in a sheltered workshop, how that came about and what her experience has been like.

Ms. Helen Leask: Yes, absolutely. This is hot off the press because she has only been there since before Christmas. This was the end result of a lot of hard work by her case managers and us, but also an element of luck. A place came up in an organization called Corbrook here in Toronto. My understanding is it's pretty much the top of the tree for adult services. We feel very fortunate. It's a sheltered workshop for people with developmental delay, so they start with the simplest of tasks, with contracts for people like Shoppers Drug Mart, like packing boxes, that sort of thing. It's run on a commercial basis, and the folks are paid to the limits of the ODSP allowance. They coordinate the whole disability allowance for how much they can earn before their disability is affected. So that's all very well coordinated.

But the really smart part about Corbrook is that if the individual says, "You know what? I want to do something different"—for example, if my daughter wants to work in a pet shop; she loves animals—they would find an employer willing to take the person on. They would train the staff and they would shadow the individual until they were well established in that job. So it's a very, very high-value and wonderful organization.

0950

Ms. Mitzie Hunter: That's excellent. Thank you so much for sharing that.

The Chair (Mrs. Laura Albanese): Thank you. This is Laura Albanese, the Chair. I know of Corbrook. It is a wonderful organization, and I'm fortunate to have it located within my riding.

I will turn the microphone over to Ms. Elliott now.

Mrs. Christine Elliott: Thank you very much, Ms. Leask, for sharing your daughter's story with us.

I think you've raised a number of very important points. One is that for people with a dual diagnosis, there is really a dearth of services in terms of residential placement, in terms of how medical personnel are able to interact with them. Too often, people get caught up in the criminal justice system unnecessarily. So thank you for sharing that. That is a theme that we have heard about, and we are turning our attention to that particularly.

Secondarily, I'm so happy that your daughter has what seems to be a very happy landing for her, but I think it shows that everybody wants the same thing. I mean, she is a person. She's a 22-year-old young person who wants to have her own place, and I imagine that some of her behaviours are subsiding, too, because she's happy where she is. So that is something we should be striving for, and then, also, taking a look at what's best for her and is also cost-effective. That's a very important point: that we need to look for more innovative housing opportunities for people because one size doesn't fit all. A group home isn't the answer for everyone. Staying with parents isn't always a good suggestion for people because, again, they are striving for that independence.

You've got us thinking here today with your presentation, and I thank you very much for that.

Ms. Helen Leask: You're welcome.

The Chair (Mrs. Laura Albanese): And now Ms. DiNovo.

Ms. Cheri DiNovo: Thank you, Ms. Leask, for your presentation. I think we all ring with your experience in the sense that you have not been served well by the system. Clearly, the system isn't working. I think we're coming to that conclusion. We've heard nothing different from any of those who've come forward, so you're not alone. That's one thing I want to make sure that you hear: Your experience may seem unique, but it is not unique in the sense that others have had that same runaround.

I was interested to hear about the assessment again. It's a theme we've picked up on, that we've got places like the DSO that spend all their time assessing and very little of their time actually delivering. That's not the way a system should work to help you.

I was very interested in your suggestion—I think it's the first time I've heard it—for a tax break on disability expenses, because, as you can imagine, it's very difficult with the direct-funding models to get up to that \$45,000 a year that you're spending. But, on the other hand, the tax-break system might be the answer.

I've left you only a few seconds, but could you say a little bit more about how you came to that?

Ms. Helen Leask: The idea of a tax break? Yes. Direct funding, as you say, doesn't even touch on as much as \$45,000, as cost-effective as that is in comparison to other options. Of course, we have Passport funding down here, but some people don't even have it, and it really doesn't even scratch the surface. So we're all scratching our heads a little about what can a system do. It just seems to me that that's a great way of helping

people out because the \$45,000 is after tax. So families are finding, if they are indeed able to find \$45,000 to support a set-up like this—this is after they've paid tax on the money. So, really, if you're middle-class kind of folk, you're earning \$70,000 to pay that \$45,000. So a tax break would really help out.

Ms. Cheri DiNovo: Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you very much, again, for presenting to us, to our committee, today.

Ms. Helen Leask: Well, thank you very much for listening to me, and if I can assist in any other way, please let me know.

The Chair (Mrs. Laura Albanese): Thank you. Have a great day.

Ms. Helen Leask: You, too. Bye-bye.

TIPES

The Chair (Mrs. Laura Albanese): We'll now welcome Jennifer Wyatt, executive director of TIPES, who is also joining us via teleconference.

Ms. Jennifer Wyatt: Yes. Can you hear us okay? I'm actually here with Dr. Sherman and Deborah Wyatt. All names were supposed to be on there. I don't know what you have in front of you. Can you hear me?

The Chair (Mrs. Laura Albanese): We can hear you, but we hear a bit of an echo. It's a bit—

Ms. Jennifer Wyatt: I'll move closer.

The Chair (Mrs. Laura Albanese): Are you closer now? Can you try again? Just a "testing 1,2,3"?

Ms. Jennifer Wyatt: Is this better? Can you hear me better now?

The Chair (Mrs. Laura Albanese): Oh, yes, much better. Thank you and good morning.

Ms. Jennifer Wyatt: Good morning.

The Chair (Mrs. Laura Albanese): Where are you calling us from?

Ms. Jennifer Wyatt: We're calling from Ottawa. We're—well, you know we're from TIPES. We have two locations: one in the Kanata area and one in midtown, toward downtown, I guess.

The Chair (Mrs. Laura Albanese): And you said you are with a doctor?

Ms. Jennifer Wyatt: Yes, Dr. Jeff Sherman. He was also on the list, and we said we would go together to make it easier on you guys.

The Chair (Mrs. Laura Albanese): Oh, okay. Thank you.

Ms. Jennifer Wyatt: We work with him. He's our supervising psychologist, so we were going to let him do much of the talking today. I already have a written document that I'd be able to send to you guys, so it kind of takes care of what I really want to say. If you're okay with it, we'll let Dr. Sherman do most of the talking.

The Chair (Mrs. Laura Albanese): Absolutely. He may start at any time. We'll have up to 20 minutes for the presentation. If it is any shorter than that, we will have

some comments and questions from the committee members.

Ms. Jennifer Wyatt: Right. Thank you.

The Chair (Mrs. Laura Albanese): You may start. Thank you.

Dr. Jeff Sherman: Hi. It's Dr. Jeff Sherman speaking. I should identify myself. I've been involved since the mid-1970s in bringing intensive behaviour intervention and applied behaviour analysis to Canada. I was involved in some research into the effectiveness of doing that in community settings, and in establishing comprehensive programs to offer this to the community at Thistletown Regional Centre. I was instrumental in creating a program called TRE-ADD.

I'm going to be speaking about the provincial Autism Intervention Program initiative that was launched around 2000. Since that time, I've been involved in both the DFO and the DSO side of things. I understand that you're aware of what those acronyms mean?

The Chair (Mrs. Laura Albanese): Yes, we are.

Dr. Jeff Sherman: Sorry. I'm just not sure of whether I should be explaining myself more as I go along.

Thank you for the opportunity to address your committee. I think that, in general, the program as it was intended—the initiative is very well-intended. I think it's helped many children across the province, however it's been delivered, but I think that the pressure to treat the many who need it, and the fact that it does take a long time, have resulted in a lot of children losing it prematurely.

I think that the problem with this is that a lot of families of children with autism need hope. The program initially raises hope, but because the pressure to treat a lot of children has caused an issue with discharge criteria, and also an issue with the number of hours and the length of the treatment provided, it's not always consistent with what the research literature says is needed in terms of some of the most recent reviews.

The macro reviews of research indicate that the number of hours and the length of time—the frequency and intensity—are not always there. Because of that, there are a number of children who are discharged, I think, before they have the opportunity to show that they can benefit from the treatment.

I'd like to address for a little while the discharge criteria as they are being presented. I think you're aware—nobody likes the term “benchmarks,” but that's kind of what they are. We're being told that, in terms of assessing—I think that if you want to look at the principles that the program is founded on, the idea that we're getting is that a child, within a short period of time—for example, two years—has to make progress in some behavioural objectives using the ABLLS; I'm assuming that your committee knows what that is. They have to make progress of two thirds of a standard deviation in standardized testing, meaning an intelligence test of some sort.

The problem with this, of course, is that, within a short period of time, we're expecting children who have

developmental disabilities to approximate the normal range of functioning. That's not always possible, but that doesn't mean that children don't make progress.

The words “developmental trajectory” are used a lot, and it's very poorly defined within the program. I've looked at the research available on developmental trajectory, and there are some very good statistical methods for predicting developmental trajectory in other populations, but these don't seem to be applied. The problem is that the discharge criteria, as they are now constructed, are kind of quasi-scientific. They're presented as scientific, but when you look at them in more detail they don't seem to address some of the problems in the literature with developmental trajectory. One of the more recent studies in 2008, for example, found that it's very difficult and troublesome to use overall IQ as a measure of predicting developmental trajectory because children with autism have very specific neurocognitive deficits that you must address, and you must individualize the program.

We're now being given these benchmark criteria: level 1, level 2, level 3, level 4; they're called foundational skills, and they seem to be the same for all children to need to progress through. They don't take into account individual differences in the children, and the problem is, we've also seen children who meet all of those and yet who are discharged because their IQs haven't improved to the normal range in a very short period of time. What I'm saying is, it's premature to look at a scientific method or a quasi-scientific method to base this charge on when the hopes of families are so invested in their children receiving this treatment.

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Some of the only research that has been done on developmental trajectories with autistic children comes from a person named April Sullivan at York University, who tried to plot the trajectories as children learn, and there are tremendous individual differences.

I've tried to get the program to say, “How do you calculate developmental trajectories?” and no one can give me an accurate definition of what that is or where exactly the cut-off is. So what it comes down to is a clinical judgment by the DSO or by the AIP provider in the region. I'm the clinical psychologist, as a DFO, who knows these children and knows what the clinical progress has been. I'm being asked to agree with the decision of the AIP psychologists, but I have a responsibility to my patients, through the college, to go with my own clinical judgment. So disagreements often arise, and it causes a lot of conflict and a lot of animosity amongst service providers, and I don't think that's very beneficial in the spirit of working together. It comes back to the idea of providing appropriate ways to judge progress.

At Thistletown, the way we tended to judge progress was through something called goal-attainment scaling, in which we would, as a team, sit down with various professionals and use our clinical judgment and what quantitative measures were available to establish actual objectives for which we would say, “Yes, the child is progressing.”

So it's just premature to use the criteria that are now being offered to us.

The other criteria that's being used is the Vineland. In this 2008 study that I'm talking about, the authors themselves used the Vineland and said this is not adequate to judge functioning. They also point out that having IQ as one of the important measures of the child's functioning doesn't actually say what their adaptive functioning is like.

The other problem with using the Vineland—and I'm sorry if I'm all over the place here—as an adaptive measure is it's only based on the parent report and it's not based on the report of the treatment personnel, who see the child within the context of treatment. So you can get very skewed gains if you don't do a comprehensive evaluation of the child's actual progress.

Going back to the developmental trajectories, when the child is discharged because he hasn't gained, say, two thirds of standard deviation or because he hasn't finished the ABBLS within a certain period of time, in a sense he's penalized for being a slower learner.

Our methods aren't that good yet. It would be presumptuous of me and, I think, a little arrogant to say that we can take every child presented to us and improve their learning in that short a period of time such that they can function within the normal range. But it's not black and white. Just because a child doesn't have the developmental trajectory of a typical child after two years doesn't mean they haven't learned and doesn't mean that they haven't learned a lot and that their functioning is much better off.

The other problem you have with IQ—and I've seen this actually happen—is, if the child has met their behavioural objectives and learning objectives, but if the standardized measures don't point to an actual gain of what's expected in that period of time, the child is discharged. There are two problems with that. The first problem with it is that it is relying on one intelligence test as a decision-making procedure. The Alberta Supreme Court just overturned a diagnosis that was made because one intelligence test was used as the measure. The other thing is, we don't know in the absolute long term what happens to the IQ over time, if you use that as the sole measure. Yes, the IQ can increase for a substantial number of children. But if you look at most of the research on IQ, you see it's stable over time. If you look at all the literature on early intervention programs in education, you sometimes get increases in IQ, but if you don't keep it up, then the IQ can return to what it was pre-intervention. That says something about the nature of learning and the nature of supports that children with autism and other developmental disabilities continue to need.

The other thing is that this program may be intended for children with autism, but it's very difficult to sort out—if you don't provide it for children with autism and developmental disabilities, then that's kind of prejudicial and discriminatory. There's a recent study from Denmark that shows that if you take IBI and apply it to children

who have a developmental disability but not autism, their rate of improvement is even greater than the rates of improvement of some of the autistic children.

If you look back at the initial study that Lovaas did in the 1960s and in the 1980s, you'll find that he did use the measure of IQ to denote success with the program, but that was only in one research study, and he needed a dependent measure to show gains. He didn't intend that to be the hallmark of whether children should get funding or not get funding over a period of time.

The other problem is—and I've seen this in my own practice—I've seen children who are discharged for apparent lack of progress, and then we have provided service for them on a private basis, and those children continue—if the program is adequate, the children are now making gains after two, three or four years of IBI and direct instruction treatment.

So I think the predictive measures we have right now are just premature in terms of saying, over the long run, what happens in giving children IBI over a shorter period of time.

There seem to be irregularities in the distribution of funds.

I'm going to leave this area now and talk about how service is provided. I have been aware that sometimes the DSO provider will try to convince the family to go with the DSO program and not the DFO program. We've certainly been—said, “Well, we base our decisions to continue treatment on the fact that we need clients,” which would be totally unethical of us to do. We try to make decisions that are in the best interests of the child. But I would also say that some of the DSO programs also need clients in order to justify their existence. So to me, having the power to distribute the hours and who gets the hours—private providers and provincial providers—and investing that in the same agency is a little bit of a conflict of interest. It's like giving Coca-Cola millions and millions of dollars and saying, “You give out Pepsi and you give out Coke now, and whoever uses the majority of the products in the future—well, we'll continue to give that manufacturer the money.” Well, there's an inherent bias in there to give out Pepsi, I think. I'm not talking about the intentions of any individual—I'm just saying how the current environment provides a predisposition to do those kinds of things. I've had a parent say to me recently in a program that we've provided privately that they were offered the service but they were encouraged to take the DSO service even though they were with a DFO provider.

We jump to the IRM, or the appeal mechanism. I've been told that I must accept the opinions of the AIP psychologist about my patients in terms of whether they're ready for school or not ready for school, and that if the parent doesn't like that, they can always appeal to the independent review mechanism. But in practice—and it was a good idea in principle—it has turned out that the independent review mechanism is not so independent because it simply reviews the paperwork and it doesn't take an independent look at whether that child has actual-

ly benefited from treatment and should have been discharged or not.

1010

In fact, in one instance I was misquoted about something I said which, if I had said it, would have been totally unethical. I didn't say it; it was put into the independent review mechanism and then written in a letter. I don't know if it's been corrected after that, but I didn't even know that it was going in.

I don't know how long I've been talking. I have a lot of other information that I would like to—

The Chair (Mrs. Laura Albanese): You've been talking for about 15 minutes.

Dr. Jeff Sherman: Okay. I should probably stop and give Jennifer and Deborah a chance to say something.

But what I'd like to say is that the treatment of children with autism and other kids with developmental disabilities is too important a decision for families and children to rely on a quasi-scientific way of trying to determine funding. We need a different way to do this. We need to do individual goal-setting, individual programming, and we need to involve a broader range, an independent way of viewing—people who are independent of the funding agency to decide whether the kids should continue treatment or not.

That's what I have to say. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. I guess this leaves about four minutes or so for others to say something.

Ms. Jennifer Wyatt: Okay. I'm Jen Wyatt. I'm the executive director. I was the person you initially—

The Chair (Mrs. Laura Albanese): Yes.

Ms. Jennifer Wyatt: I have a master's in counselling and psychology and I also have other education through the States for applied behaviour analysis. While I'm the executive director, I also do a lot of the clinical work, like supervising therapists and providing treatment.

I don't want to get too much into the issues. I've read the Auditor General's report and I can tell you, as a service provider—and I should mention we're a children's charity. With all the families we have served over the years, I can definitely support much of the issues that were brought up in the Auditor General's report. We've definitely witnessed many of them. But what I really want to focus on is maybe coming up with some suggestions or ideas on how some of it could be fixed.

I know that the government has to support both public and private, so is there an opportunity for government to reconsider allocating funds? I know that unions drive the price up at government programs significantly, which was also highlighted in the Auditor General's report, that the DSO program is significantly more expensive than the DFO. I am not suggesting that you cancel the program; I'm just wondering if there's a way to make them compete so maybe the money goes to the parents, and if they want to go to a DSO program, they can then go to a DSO program, but they get the same amount of money as everybody else.

I also wonder if government could be doing something more in the area of emergency care for families who have a child who is having severe, severe behaviours. At this point, in Ottawa, there is nowhere to really send them. They are taking up hospital beds and they're being medicated because they don't really know what else to do with them, so if they can do more of an awareness.

I was at a hospital yesterday speaking with the vice-president of a program that works with children with autism, and they didn't even have stuff to give to the families on places to go while the families are sitting on the wait-list. So I said, "You should probably contact all the service providers and we can send stuff in and at least the families have something to do while they're sitting on the wait-list." Obviously, in a perfect world that wait-list would actually go away.

And then, is there something that the government can do on the idea of education or counselling and coordinating? While the IBI is really important, there's a lot that goes into it between dealing with service providers, pediatricians, schools and that sort of thing.

That actually brings up my next point. There is a program through the government agency; I believe it's the Connections program. I can tell you, as a service provider, I've gone to a few meetings and there are so many people sitting around the table, I can't imagine how expensive it is for taxpayers. On average, there are probably about 16 people sitting at that table, and they're all paid either through the school board or through government for the autism program. I just think, as a taxpayer and a service provider, there are probably different ways of allocating funds that would be more beneficial and efficient. Then you would also see the children get the funds earlier and hopefully end up with better results—do the ultimate goal of the money and get into classrooms with typical peers.

The Chair (Mrs. Laura Albanese): Thank you very much to both of you for your presentation this morning, for your suggestions and for providing us with an insight on your point of view on the issues. We thank you very much. Our time is unfortunately up and I have to move on to the next presenter. We're on a very tight schedule this morning, but we want to thank you for participating in this discussion.

Ms. Jennifer Wyatt: Thank you.

Dr. Jeff Sherman: Thank you for listening.

The Chair (Mrs. Laura Albanese): Thank you. Bye-bye. Have a good day.

MR. MICK KITOR

The Chair (Mrs. Laura Albanese): We'll now hear from Mick Kitor. Hello?

Mr. Mick Kitor: Good morning.

The Chair (Mrs. Laura Albanese): Good morning. How are you today?

Mr. Mick Kitor: Outstanding. Yourself?

The Chair (Mrs. Laura Albanese): We're good. We're here in Thunder Bay and enjoying our day. Where are you calling from?

Mr. Mick Kitor: Ottawa. I wasn't able to get on the agenda for Friday. There was a space available to phone in and I figured being heard is better than sitting in the shadows. I still plan on attending on Friday.

The Chair (Mrs. Laura Albanese): Excellent. Yes, and we want to hear from as many people as possible, so the fact that you are able to call in today is really wonderful for us. You will have up to 20 minutes for your presentation. If the presentation is not that long, then that will leave some room for questions from the members of the committee. You may start at any time.

Mr. Mick Kitor: Sure. I'm going to assume everybody loves to add some figures and wants everybody to rehash the Auditor General's report—I'm kidding.

The reason I took the time and stayed up until five in the morning putting this presentation together last night is that I need something from you as MPPs. Some 30,000 children in Ontario need something from you. What do they need? Well, equality and fairness. They need the same quality of autism services regardless of where they live. They need value for the money being spent.

Timing is everything. We invest over \$150 million in IBI therapy. I'm assuming everybody knows IBI therapy and I don't have to explain it?

The Chair (Mrs. Laura Albanese): Yes, we know what IBI stands for.

Mr. Mick Kitor: According to the Auditor General's report, we invested three years too late. We also don't invest in IBI therapy for the kids who benefit from it the most, those kids with milder forms of autism.

Then, the last thing that we need is oversight and ownership. You're born with autism. It's a lifelong condition. It goes from baby to student to adult. When we look at the ministries that it touches, it's the Ministries of Health and Long-Term Care, Children and Youth Services, Education, Community and Social Services. This year, if we look at—and there are stats that range all over the place: Hard stats are one in 77, but it could be as high as one in 50 for children being born with autism. That means 1,600 children will be born this year who have autism. They need somebody to ensure that they don't fall through the cracks between the ministries.

So, digging into equality and fairness—by the way, is my voice okay? Everybody can hear me fine?

The Chair (Mrs. Laura Albanese): Yes, we can hear you very well.

Mr. Mick Kitor: I'm not—

The Chair (Mrs. Laura Albanese): And we're following your presentation. We have a copy of it.

Mr. Mick Kitor: Perfect; I didn't know. So, if you have a child with autism, one of nine people has god-like powers over your family. When I say "god-like powers," it sounds like total hyperbole, but it's not, and I'll explain. Their decisions will determine, quite possibly and very seriously, if your family can keep their home, if you can afford to have more children, when and if you might be able to retire—sorry; it's kind of emotional—and what type of life our children could expect. These people are the regional clinical directors of the Autism

Intervention Program. They're not even government employees; they're contracted, and they've been given this power by the Ministry of Children and Youth Services.

Clinical directors—it seems like, as a parent who has gone through the system—are free to interpret the autism intervention guidelines however they see fit, implement their own agendas and discriminate against the very children they're being engaged to serve.

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These people can revoke eligibility. A child can be deemed eligible, go on the wait-list and then hit the top of the wait-list, and some agencies, Ottawa or the CHEO eastern region in particular, can retest that child when they hit the top of the list and then say, "Oh, they no longer qualify." Nowhere is that actually said in the guidelines. They can cut the hours your child receives or stop therapy completely. They determine who receives therapy, how many hours a week they get and how long it lasts. This ranges wildly by region. The Auditor General's report has a great graphic that actually shows the length of service either with the direct funding option or with the direct service option.

These nine regional service providers, at least to a layman like myself, operate with little or no oversight by the Ministry of Children and Youth Services. Instead of holding the regional providers accountable, it seems to me that parents are abandoned by the Ministry of Children and Youth Services. They know that families are going to be forced to choose between paying for private therapy or paying for legal services if they want to hold the regional providers accountable. Parents are frightened to come forward. They live in fear of the power and reprisals that could take place from the nine regional clinical directors.

I got an email last night, and the reason I got the email is that I'm looking to pitch a story to the CBC about the disparity between length of service in Ottawa versus the rest of the province. I had a parent come back to me with the following: "I'm not able to speak to the reporter about my experiences because my child has not been discharged yet and I'm worried about retaliation from Lise Bisnaire," the director of the CHEO autism intervention program. That's not right. Parents shouldn't have to be worried that they can be bankrupt if they dare blow the whistle and say something is not kosher.

How much power does a clinical director have over a family? I'll illustrate with my family. We have invested over \$77,000 in private therapy and a private diagnosis for our son. We raided anything that we had that had value in it: our retirement savings; we borrowed against the equity in our home. Our parents gave us thousands of dollars—they're retired. It's really costly to have a kid with autism, if you want to give them the best trajectory possible. The odds that if we have a second child that child will have autism are even greater than the 1 in 77 if you've never had a child before. We just don't have another \$77,000 for private therapy while we wait on the wait-list. My wife and I pray that our son is going to find

somebody to love him, because after we die—we can't afford to give him a brother or sister.

The independent review mechanism that reviews decisions to discharge or eligibility decisions that the regional providers make is a farce. A criminal in Ontario is innocent until proven guilty, but we can't give the same benefit of the doubt to our kids. Why is the burden of proof not on the regional provider to justify removing therapy or denying therapy, but rather on a parent to prove that it shouldn't be removed or that they do deserve therapy?

A fair process would ensure that if an error was made by a regional provider—and we're all human; it can happen—no family would be bankrupted and no child robbed of their future. Instead, the deck is stacked against families and kids. If you want to make an appeal as a parent, you've got 20 business days to request a review of the decision, or the decision stands. There's no discovery process. Before you write your request for a review, you don't actually get to see any of the test results; you don't get to see any of the files and all the paperwork that they've built up to justify discharging your child. In the very first meeting that we had to say that our child was eligible, they discussed discharging our child—in the very first meeting.

The regional providers choose what gets omitted and what gets included in the documentation that's sent to the independent reviewer. If the regional provider or the independent review mechanism administration do not meet the time deadlines or their obligations as outlined in the process, the decision won't be reversed. There's no mechanism for the decision to be reversed other than a psychologist, upon reading the cooked documents that are sent to them by the regional provider, disagreeing with that. It doesn't happen very often.

In our case, a private psychologist who advocated on behalf of our child was retroactively prohibited from supervising direct funding for IBI programs. She wasn't sanctioned by the College of Psychologists. This decision was unilaterally made by CHEO, the regional provider, at their sole discretion.

My son is going to be discharged by June 21, four days before the end of the school year. He is expected to go 67 days without therapy and have a completely smooth transition after the province and ourselves have invested to the tune of \$180,000 in his therapy. Right when we're getting close to the finish line, we're going to say, "Well, let's not run that last 10 metres of the 100-metre sprint."

When we appealed this decision, CHEO chose not to submit that part of our argument about why our son shouldn't be discharged. They just didn't do it, so the review mechanism didn't even consider our argument.

There is an expert committee that was formed to help parents of children with autism in the many challenges that they face. I read that from an article. I find it funny that there's no parental representation on that committee. There's one person who has a child with autism, but they also have a PhD and work in the field of autism. He's not

going to have the same typical dealings with the system that a parent is.

What do I mean by equality and fairness? What do I want? I want you to hold the Autism Intervention Program regional providers to account. They should be evaluated on the effectiveness and outcome of the therapy, not on the number of children on the wait-list.

The decision to make eligibility decisions and discharge decisions should not rest in the same agency that administers the wait-list. That's like paying the foxes to guard the chicken coop. We need to reverse the burden of proof when it comes to eligibility and discharge decisions with regard to the independent review committee. It should be therapy until proven ineffective.

What did I mean by value? Why did my family spend \$77,000 on private diagnosis and therapy? Well, I'm going to read some quotes from the recent Auditor General's report. I won't go very long. Please excuse the hyperbole; you know how excited accountants can get and how they like to exaggerate—not.

"Early diagnosis and treatment of autism might reduce the need for more supports and services later on in life." Sounds reasonable to me. You help a child catch up to his peers earlier, and the symptoms are less severe and they can integrate quicker—less cost to the whole system.

"We estimated that children with autism are diagnosed in Ontario at a median age of a little over three years." They're supposed to be in therapy by then. You can diagnose a kid when they're 18 months old. In Ontario, you can't access services for autism without a diagnosis.

Another quote: "Children who start IBI before age 4 do better than those who start after age 4." Makes sense. When they're that young, their brains are knowledge sponges, but it starts to fill up, and they absorb information slower and slower as they age, the problem being that the median wait time for children with autism in the three areas that the Auditor General visited was almost four years. It's a little bit of a Catch-22 there.

Due to the long wait-list for IBI services, children are not typically starting IBI until almost age 7 in Ontario. We know they need to start before age 4. That's three years after the window started to close.

1030

What do I think we should do for that? Well, once your child is deemed eligible for IBI services, you should be able to apply for a student loan, except in this case, the student's going to be our autistic child, and it's going to be an autism loan.

Parents will take on the liability, start the therapy immediately when it does the most value, and when their child reaches the top of the wait-list, then they'll be reimbursed. You're going to be spending the money when it's the most effective. Four years aren't going to be wasted waiting for funding. Four years is a hell of a long time when you're waiting for your child to say, "I love you, Daddy." You wouldn't have to choose between financial ruin and your child's potential.

IBI therapy would be more effective. School systems would not be dealing with kids who haven't had any

therapy yet, so they wouldn't have to spend as much on EAs and special education accommodations.

To give you an idea of how much three years' difference can make, I did a little research last night. Apple released the iPhone in June 2007. The share price was \$118. Three years later, they introduced the iPad. The share price was \$228. When would you rather have invested \$114 million? That's how much we invest in our kids each year. As of last night, Apple was trading for \$535 a share. When you invest makes a huge difference.

Despite an outstanding ROI on therapy, according to the Auditor General, the kids who would benefit the most from IBI therapy are ineligible. There's scientific research that shows that kids with a milder form of autism have a better outcome with IBI.

We're not talking about, "Oh, maybe these kids with milder forms of autism won't have to be dependent on the government." They could actually be scientists. They could be engineers. They could be computer scientists. They could be programmers. They could contribute, but we choose not to spend on them, not to invest in them.

So what do I want for value? I'd like to see government-backed autism therapy loans. Get the therapy earlier, and get more effective treatment. I'd like to see children with milder forms of autism receive the therapy so that they can contribute to society, and there's a lot they have to contribute.

The last point I have is oversight and ownership. This is a ministerial hot potato. You don't have to be a Queen's Park government insider to figure out that if four provincial ministries are responsible for autism services, ultimately no ministry is responsible for autism services.

The rate that autism is being diagnosed—it's being diagnosed more often than diabetes, cancer and AIDS combined. That's according to the CDC and US data.

The Auditor General estimated that between 30,000 and 35,000 children were living in Ontario with autism. That's about the population of Stratford. When you factor in parents, grandparents and siblings, now you're talking about the population of Windsor. That's who we're failing right now: a city the size of Windsor in Ontario.

Autism is being diagnosed at epidemic proportions. Ontario needs to plan and execute a comprehensive response proportional to the disorder that recent CDC reports say affects one in 50 children.

Thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you for your compelling presentation. We have about a minute left over for each party to make a comment. We'll start with the NDP. Miss Taylor.

Miss Monique Taylor: Thank you so much for your time today and for bringing your family to our table. We could definitely hear the emotions that your family feels, and fairly so.

I'm glad that you brought up your thoughts on the independent review process and the mechanism, because we definitely haven't heard enough at the table about the performance measures and the benchmarks that families go through and how unfair that system is. We heard it

from our previous speaker, and now we're hearing it from you.

It's an important piece of the puzzle that needs to be brought to the table that others need to be aware of, and hopefully we can make some good recommendations to go forward with that.

Mr. Mick Kitor: The problem being is you're not going to hear about those until kids are discharged, because parents live in fear of reprisal.

Miss Monique Taylor: You're absolutely right.

Mr. Mick Kitor: So until there's a method for providing anonymous input, it's not going to happen. The decisions are arbitrary. Our son goes to a therapy centre that's been in private practice for autism for over 10 years. They told us our son was the candidate in their history who has responded best to IBI. They could not understand why he was declined and his therapy terminated.

Miss Monique Taylor: That's right, and I think that's because there is no clear process on benchmarks and performance measures. And we've heard about the wait-lists. I've been hearing a lot from families who say, "Our child has lost their treatment because the wait-lists are high and they need to move on"—

The Chair (Mrs. Laura Albanese): Sorry. I have to intervene, because otherwise the time will not be divided equally. But you both made your point. Thank you.

Ms. Hunter, a brief comment.

Ms. Mitzie Hunter: Thank you, Mr. Kitor, for your very passionate sharing of your story. We have heard your concerns, and they have been shared by others as well. They really have underscored that children with autism and other developmental disabilities need to be supported so that they can contribute to society and live as full a life as possible. I think that is the spirit in which we are conducting these hearings. Our intention is to ensure that we coordinate the delivery of programs and services across the provincial ministries and ensure that that is being done in the best possible way. Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Hunter. Now Mr. MacLaren.

Mr. Jack MacLaren: Hello, Mick. Good to hear from you again.

Mr. Mick Kitor: You too, Jack.

Mr. Jack MacLaren: You and I know each other well. You've articulated your problem to me a number of times, that you're yet another desperate family in eastern Ontario where the system has failed you. You've done a wonderful job of searching out private sector IBI treatment from people who do an excellent job of delivering it and offer hope for you and your wife, and you find great frustration with the private sector, which is the regional deliverer of—

Mr. Mick Kitor: The public sector, yes.

Mr. Jack MacLaren: Yes. So you've done a wonderful job of articulating the issue and the problem.

I think we need two things: better oversight and accountability of how government does its job of delivering the service that you need, and to provide more funding to help you and other families like yours because of

the huge cost that's developed, and do it in a more timely fashion. Would that sum up most of what you would be looking for?

Mr. Mick Kitor: It would. The other thing that I would also point out is that for every parent that's able to articulate what the problem is, there's probably 10 or 15 or 20 more who know there's a problem but can't articulate it.

The Chair (Mrs. Laura Albanese): And that's very evident to us. We thank you very much again for your presentation this morning, Mr. Kitor.

Mr. Mick Kitor: Have a great day.

REV. MAGGIE HELWIG

The Chair (Mrs. Laura Albanese): We'll now be joined by Ms. Maggie Helwig. Hello?

Rev. Maggie Helwig: Hello.

The Chair (Mrs. Laura Albanese): Good morning. Where are you calling from?

Rev. Maggie Helwig: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): From Toronto. You'll have up to 20 minutes for your presentation this morning to the members of the committee. If it's any shorter than that, we'll have some time for comments and questions. You may start any time you feel ready.

Rev. Maggie Helwig: Okay, and this is going to be a fairly personal and anecdotal presentation, which isn't what I normally do. I'm an Anglican priest and I'm the mother of a young woman who has autism and an intellectual disability and who just recently turned 18.

I want to stress at the beginning that I understand very well that I'm speaking to you from a position of relative privilege. I am a highly educated professional who speaks English as a first language, and I have a partner who is able to work part-time and mostly from home so that he's able to act as a primary caregiver. Obviously, our family income is limited by the need for him to work part-time from home and by the fact that working in the church isn't a very highly paid job, but still we can meet our material needs and have some money left over for our daughter to access services. All of that, I'm aware, puts us in a very privileged position compared to many, many families.

On the other hand, my daughter, at the age of 18, has to have a responsible and familiar adult with her at all times. She can't travel on public transit by herself. She can't go to a store by herself. She can't be in school without support. She'll never be able to live independently.

1040

She understands what it means to have a job, and she wants to have a job, but she's going to need a lot of support to be able to achieve that goal.

She doesn't have any siblings, and she isn't close to her cousins, so there's no certainty about who's going to be there for her when her father and I aren't around. So, despite our relative privilege, we do live in a constant state of anxiety about her future.

With regard to developmental services in Ontario, I have to say our experience has been mixed at best. Our experience with the transition from the youth system to the adult system has been profoundly discouraging and, I would say, frightening.

My daughter was diagnosed at the age of three and a half. At that time, IBI was only offered up to the age of five, and the waiting list was long enough that we were advised that there was really no point in putting her on the list. She has never received any funded IBI intervention. I know that the age limit has been raised. There may have been some way we could have accessed it later; if there was, nobody ever told us what it might be.

We have paid for her to have specialized educational help, speech therapy, occupational therapy. We've done that with help from her grandparents, and we're very lucky that we've been able to do that because, really—and I gather this reflects the experience of the previous speaker as well—everything we've been able to access has been in the private sector. We've really never had any funded therapeutic or educational interventions, with the single exception of a few weeks of behavioural intervention focusing on social skills, which she received about a year and a half ago. So that's a few weeks over the course of her entire childhood and adolescence. Everything else has been private sector.

When she was about six or seven, and we had essentially no help or supports in place, we were in crisis at that point. We couldn't cope with her needs and behaviours. We didn't know where to turn. Again, I'm someone who's really unusually well qualified to navigate bureaucracies, but I had so little guidance that what I did was to start flipping through the phone book and calling organizations that I thought might help.

I found Community Living. I am very grateful that I did. A worker came to visit us and told us at that point about Special Services at Home funding and Assistance for Children with Severe Disabilities, connected us with a parent support group and offered us advice and moral support for some years. No one had told us about these basic programs until that point.

We never got a great deal of funding from Special Services at Home, but it was enough to have a respite worker for a few hours on weekends, and some help in sending her to appropriate day camps. We've never been able to afford an overnight camp; that's out of the question.

Although I understand the reasoning behind the re-organization so that your lead agency is simply set by diagnosis, that means we don't have access anymore to Community Living, which was a support to us for years. I'm sure that Surrey Place is doing the best they can. We did access the one very short-term program I mentioned via Surrey Place. But autism is a really, really common diagnosis; their caseload must be enormous. We have very little communication with them. I don't know if we have an assigned worker at Surrey Place; we probably do, but I don't know who it is. We haven't heard from them. I don't know who to call.

Of course, when my daughter turned 18, we lost Special Services at Home. We lost Assistance for Children with Severe Disabilities. There are, in theory, adult programs to replace these, but in practice, at this stage, we have nothing.

I started calling ODSP and Developmental Services Ontario shortly after she turned 17, and I was told at that point that it was too early to start making these calls. She's now 18, and we're not receiving anything from either service. I have phoned our ODSP case manager repeatedly to ask when she will be assessed for eligibility; I have invariably gotten voicemail. I have left messages; I have not been called back.

My daughter should be receiving ODSP or, at the very least, be in the process of establishing eligibility, especially when I went to the trouble of making contact very early. She's not getting ODSP. I have no idea when she might be assessed for ODSP.

I did at least speak to our assigned worker at Developmental Services a few days before her 18th birthday, so I give them credit for returning my call. Much earlier, I had faxed in her diagnoses and was informed that she was eligible for DSO services on the basis of her disability, that she was genuinely disabled, and that the next step was an interview to determine her needs and what suitable programs might exist. So when I spoke to our worker last month, I asked when that interview might happen. What he said to me was that she's on a very long waiting list, about a year and a half long. He couldn't tell me when she might actually get to the top of that waiting list. However, he said, "There's no money in the system anyway, so we couldn't offer her anything. So it doesn't really matter when she gets the interview. There might be money in the system again someday, but we don't know." You can imagine that it was extremely discouraging to hear that the assistance for which my daughter is eligible may or may not ever be available to her at some point in her life.

ODSP is not returning my phone calls. We are paying out of pocket with no support whatsoever for her school, for her respite worker, for her extracurricular programs, for her occupational therapist. We are managing this with help from our extended families. As long as I'm working full-time, we can do this, but it makes it very difficult to put money away for her future. She will need support all her life, and she will outlive her parents by decades.

My daughter wants to be a contributing member of society. She's learning to cook. She goes to work with her father. She works at school to learn basic office skills. She's really doing her best to develop the skills to take her part in society, but there's no structure to help her develop and apply these skills. There's no prospect of appropriate supported housing, maybe not ever—maybe when we die. I don't want my daughter spending her adult years watching television in a nursing home after her parents die, which I know very well is a possibility because I know people it happened to.

I also don't want my daughter to end up homeless, and I know that's a possibility because in my job in the

church I deal with many people on the street, and as someone who knows developmental disability, it is blatantly obvious to me that many of them are homeless, are marginalized, are desperately poor because they have developmental disabilities and they are not getting the support and the help they need. They can't care effectively for themselves and society is not caring for them, and they come to my church for a sandwich and I think, "Is this my daughter's future?"

If I, as a person with privileges and options, feel this much frustration and terror about my child's future, I can only imagine what it's like for people who can't pay for private sector services, who are trying to navigate the system in a foreign language, who have children with more severe behavioural challenges than my daughter has. I hate to even think what it's like for so many people out there because I know what it's like for us, and I know that we're coming at this from a very privileged place.

That's all I have to say at this point. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for sharing your experience with us so intimately.

We have about three minutes for each party to ask questions, and we will start with the Liberal Party and Ms. Wong.

Ms. Soo Wong: Thank you, Ms. Helwig, for sharing your story with the committee. There are a couple of us on the committee from Toronto, so first thing's first, I need to ask you which riding, which area you live in so that we can follow up with you off-line to ensure that—

Rev. Maggie Helwig: I'm not doing this to try to get help for myself personally; I'm trying to do this so that the system works better—but I live in Trinity-Spadina.

Ms. Soo Wong: Okay. We would like to get some personal information from you off-line, so I wanted to follow up on that piece.

The second question I need to ask you is regarding the services that you received when your child was in school. So I need to ask—

1050

Rev. Maggie Helwig: She has never been in public school.

Ms. Soo Wong: She was never in public school?

Rev. Maggie Helwig: Except in kindergarten.

Ms. Soo Wong: In kindergarten. In terms of improvement—because this committee also will be providing recommendations to the Legislature. Can you share with us, in terms of priorities, what you would recommend this committee consider? I heard the frustration about the lack of information shared with you and that you tap on your own family and your own personal resources to ensure some resources—

Rev. Maggie Helwig: Okay, are you talking about youth services or adult services?

Ms. Soo Wong: Well, currently for your daughter.

Rev. Maggie Helwig: I think clearly the adult system is obviously incredibly poorly resourced. I think maybe people think there is more point in putting resources into the youth system because maybe you can make them be normal and then not have to fund it. But the adult system

is hugely, hugely poorly resourced. There just needs to be more resourcing in the system as a whole, but especially for adults with developmental disabilities.

Ms. Soo Wong: Okay. My last question to you is with respect to your comments about your daughter's unemployment issues. Are you getting enough—are you getting any—services and support for your daughter with respect to her training and employment opportunities out there in the community?

Rev. Maggie Helwig: At this stage, no. I mean, we have talked to her school. Her school is also looking to see if they can find any possibilities. We have enrolled her in a continuing education course at George Brown, but this is all stuff that we're looking for ourselves. We're getting no support at this stage in any formal way, no.

Ms. Soo Wong: Again, thank you very much. We will definitely want to follow up with you with this good stuff.

The Chair (Mrs. Laura Albanese): And now, Ms. Sylvia Jones.

Ms. Sylvia Jones: Thank you, Maggie, for sharing your story. I have a few questions because you are not the first parent who has talked about the frustration of the transition from youth to adult and that process. You mentioned that with one exception of a couple of weeks, all the services that you have been able to provide to your daughter have been through what you had found privately. Is that accurate?

Rev. Maggie Helwig: It is, but as I said, we have had at least funding from Special Services at Home and Assistance for Children with Severe Disabilities. That helped pay for the private sector service.

Ms. Sylvia Jones: But not until Community Living made you aware of it.

Rev. Maggie Helwig: Yes.

Ms. Sylvia Jones: Which I guess in and of itself is disturbing, that you would have had to wait until your daughter was—you mentioned six?

Rev. Maggie Helwig: I think it was when she was about six, yes.

Ms. Sylvia Jones: I mean, kudos on you for your advocacy, but it sounds like there were numerous opportunities for people to share what little limited opportunities there were and they didn't even do that.

Rev. Maggie Helwig: Yes, I think there are a lot of communication problems in the system. As I said, there may be other programs that we should be trying to access now that I don't even know about. I'm never confident that I know about what's out there because I know that things are so fragmented.

Ms. Sylvia Jones: And it is a moving target, of course. Things change. If you were making one recommendation to us as a committee trying to formulate our suggestions, what do we need to do first and foremost? What would have helped you the most when your daughter was diagnosed?

Rev. Maggie Helwig: I think at the point of diagnosis, parents need a lot—I mean, it's hard to receive informa-

tion at that point in a sense because there's the shock of the diagnosis and the coming to terms with that. There needs to be some kind of continuing relationship set up. You know, if you get a diagnosis and a pile of information thrown at you at that point, I'm not sure how capable many families would be of processing it at that time.

Ms. Sylvia Jones: Fair enough. We've talked about the concept of a navigator, which would essentially take you through the stages. You would be familiar with that concept in your professional role. Is that something that you could have seen value in?

Rev. Maggie Helwig: I think that would certainly be helpful. I think until the system is better resourced, the navigator is going to be in much the same position as our worker at DSO, saying, "I can't offer you anything anyway." But I think that having a navigator for families certainly would be helpful, absolutely.

Ms. Sylvia Jones: Okay, thanks for sharing it.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: Hi, Reverend Helwig.

Rev. Maggie Helwig: Hello. Hi.

Ms. Cheri DiNovo: Cheri here. We know each other.

Rev. Maggie Helwig: Yes, we do.

Ms. Cheri DiNovo: Thank you very much for your advocacy work. What you have brought forward, I just wanted to reassure you, is not unique. We have heard that the system is broken, maybe irretrievably so, from a number of folk who have come forward. Your experiences—of course, as you probably know, you're not alone. I just wanted to say that first off.

To follow up on what Ms. Jones had asked about suggestions, one of the speakers today was talking about the particular challenges of an ASD diagnosis and, again, getting treatment there. You say your daughter was not in school at any point—

Rev. Maggie Helwig: She has been in a private school since kindergarten.

Ms. Cheri DiNovo: Okay. Did she get ABA or IBI treatment anywhere along that, as part of the schooling?

Rev. Maggie Helwig: Her school is based on IBI principles.

Ms. Cheri DiNovo: Right, okay.

Rev. Maggie Helwig: One of the things that many families have advocated for, for some time, is that those schools—there should be a way that funding for IBI can happen through schools which use IBI principles, like her school.

Ms. Cheri DiNovo: I hear you. Again, you've gone to the private sector because that's all there was.

Rev. Maggie Helwig: Yes.

Ms. Cheri DiNovo: Did you check out, though, the public school system? They are also supposed to provide—we've heard of EAs. We've heard of problems with it, but—

Rev. Maggie Helwig: She was in the public sector for junior and senior kindergarten, and it was pretty much a disaster.

Ms. Cheri DiNovo: It was a disaster.

Rev. Maggie Helwig: She was assigned an EA for part of the time. The EA had no specialized training and was not familiar with IBI or with autism spectrum whatsoever.

For grade 1, what she was offered was placement in a kind of mixed special-needs class, which again would not have included any IBI component or any specialized training in autism or autism spectrum disorders.

Ms. Cheri DiNovo: Thank you. My colleague has a question.

Miss Monique Taylor: Hi, Ms. Helwig. This is Monique Taylor. I'm just curious: What was your experience in the private school with the IBI training? I know that the curriculum would have been exactly what your child had needed, but for sociability aspects, could you explain what that experience was like for her, without her being in the "normal" realm of children?

Rev. Maggie Helwig: I think that it has been a good experience for her. Particularly for children with autism spectrum who find social interaction so very difficult—

Miss Monique Taylor: Right.

Rev. Maggie Helwig: —that's actually the most nightmarish part of the public system. That's the hardest part to navigate.

When she's in a specialized environment, where a lot of attention is paid to supporting and developing the ability to interact with other people, that has been something that she would not likely have had anywhere else, and I have seen her behaviour improve tremendously. I have seen her social skills improve tremendously.

If that kind of very intensive social skills training could have happened in an environment with neurotypical children, perhaps that would have been the ideal. But the intensity of the focus and training on behavioural and social skills, I think, is the crucial thing. She interacts with neurotypical people at church and in other parts of her daily life, and—

The Chair (Mrs. Laura Albanese): Ms. Helwig, I'm sorry. I'm going to have to interrupt you, because our time is over.

Rev. Maggie Helwig: Okay, sure.

The Chair (Mrs. Laura Albanese): But on behalf of Miss Taylor, what is the name of the school?

Rev. Maggie Helwig: Kohai.

The Chair (Mrs. Laura Albanese): Kohai. Thank you very much for your presentation to the committee today.

Rev. Maggie Helwig: Okay, thank you.

The Chair (Mrs. Laura Albanese): It's very much appreciated. Have a good day.

Rev. Maggie Helwig: You too.

MS. SILVANA CACCIATORE

MR. BRIAN JACQUES

MR. KEN MACLAM

The Chair (Mrs. Laura Albanese): We'll now call Silvana Cacciatore to come forward. She's the first in-

person presenter of the day. Good morning and welcome. I know you were listening in the back, so you know you have 20 minutes for the presentation. Please state your names and your titles, if any, before you start, for the purposes of Hansard.

1100

Ms. Silvana Cacciatore: Okay. Before we get started, we want to just kick off our bargaining campaign. It's called Turnover Tuesday, so we'd like to share turnovers with you today. And we gave out little pamphlets.

The Chair (Mrs. Laura Albanese): I believe each member got one.

Mr. Brian Jacques: My name is Brian Jacques; I'm a support worker for Community Living Thunder Bay. I've been a support worker for 10 years.

Mr. Ken Maclam: My name is Ken Maclam; I'm also a support worker at Community Living Thunder Bay, for about 10 years. I'm also representing the provincial youth committee for OPSEU.

Ms. Silvana Cacciatore: Should I start talking?

The Chair (Mrs. Laura Albanese): Yes, please start talking—

Ms. Silvana Cacciatore: Okay, I'll start. I would like to start by thanking you for giving us the time today to address you on the crisis we face daily as developmental service workers. As I said before, I'm Silvana Cacciatore, and Brian and Ken are with me also. I hope that at the end, we will all be able to answer questions.

I am a front-line developmental service worker at Avenue II Community Program Services in Thunder Bay. I have worked in developmental services for over 25 years; I have worked at Avenue II since 1991, and I have seen a lot of changes. We are a relatively small agency and have just 100 staff members. Of these, approximately half are casual, a quarter are part-time and the remaining quarter are full-time.

Our budget has not changed in more than four years. As costs increase, our budget does not keep pace with inflation. That means there is less of everything. The budget is stretched so thin, and the expectation put on everyone affected is to do more with less.

If I take a vacation day or call in sick, the people I support have no access to services. There is no budget for backup staff, so individual hours are cancelled, which often leaves family members in crisis.

There is less money for support time at my agency. I remember a time when the focus of our job was to integrate individuals into the community through employment or recreation. This can no longer happen unless they use Passport funding.

The Passport funding system does not provide enough for people's needs. I see families every day who have very limited access to services with the individualized funding they receive. Families have commented that they have been approved for Passport funding but are still waiting to receive the money. Some of them have been waiting a long time without access to the services they have been promised.

A lot of time, effort and money is being put into meeting the requirements of the ministry, such as quality assurance measures, fire regulations and health and safety. Yes, these might be important, but when your agency has to worry more about meeting requirements and deadlines, filling in the appropriate forms and doing the paperwork, these all take away from our limited resources. The focus is taken away from why we are really there: for the individuals we support.

And I don't understand how it is that QAM is valued highly while Passport system funding encourages using non-qualified, uninsured service providers. This seems to me to be a double standard in respect of quality care and in respect of the people who depend on developmental services. Due to a lack of Passport funding, families can only afford to hire people with no education, no first aid, no NCI, and no criminal reference checks are needed.

There is a very high turnover in staff at the agency where I work. Half of us are casuals who have to work two or three jobs to survive, and often these people end up quitting. This is not good for the people we support.

I myself have to work two jobs. I have two kids. I can't make ends meet with just one job, even though I have full-time work and have been working here for over two decades and have a university education.

The saddest thing for me, however, is knowing that at the agency where I work, we can't support anyone new. Unless someone actually passes away, not one single person in Thunder Bay can expect to receive services at our agency.

I know what that means for the people who are on the wait-list. There are more than 800 people in the Thunder Bay area on the wait-list for day services, and more than 200 people in Thunder Bay on the wait-list for residential.

Can you imagine what it is like to be a parent or a family member caring for a person with a developmental disability? When their kids were 18 and under, they were able to go to school and receive services. Then they turn 19, and the funding is cut: They have to stay at home with nothing to do and nowhere to go until they get off of the wait-list. They will be at home until someone dies.

More than 10,000 OPSEU developmental services workers want to know how the government plans to fix the crisis in services for people with developmental disabilities.

It is time for a serious commitment to properly funding developmental services. Ontario families are stressed and pushed to the limit, waiting for access to services. Lack of adequate funding means there are not enough staff to meet the needs of people waiting for services.

Finally, I just want to say that while I am grateful that you have all taken the time to visit Thunder Bay, I am disappointed that there is not an MPP from the north on this developmental services select committee. We have very specific challenges; for example, with regard to travel time to access care and accessibility of specialized support resources in smaller communities.

Thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We have about—sorry, I have to calculate here—four minutes for each party. We'll start with Ms. Elliott.

Ms. Silvana Cacciatore: It is okay—Brian wants to say something.

The Chair (Mrs. Laura Albanese): Oh, you still want to speak? Okay, please, go ahead. Sorry.

Ms. Silvana Cacciatore: Brian wants to give a story. I forgot; sorry.

Mr. Brian Jacques: I just want to say a story, because I've been a support worker for 10 years, and it's extremely frustrating when we don't have enough staff. I've been directly hit with that because in a home that I work with, I work with three gentlemen. One has autism, and the other two are undiagnosed and could potentially have mental health issues; they have never been diagnosed. The story I want to share is that due to lack of funding and a staff shortage, I actually was assaulted and had a concussion because there was not enough staff on. That is extremely frustrating to me because the only person who cared in the agency and even came to me was my direct team leader. That is sad. The person who assaulted me, it was not his fault; it's the fault of all of us—not having the funding to support people's needs. Have any of you ever been to a group home and actually seen what happens? It's sad that we cannot support the people with the amount of staffing they need. It's extremely sad. For staff to get assaulted on a daily basis is not right. The people who we're trying to support—it's not fair to them, and it's not their fault. We don't have enough staffing. That's where things need to change.

The Chair (Mrs. Laura Albanese): Thank you, and thank you for the apple turnovers that you brought, which are really delicious. I will pass it over to Ms. Elliott.

Mrs. Christine Elliott: Thank you very much for coming today and for your presentation. Just a couple of comments: one is about your concern that there isn't a northern member on this committee. What I can tell you is that we are really interested in finding out about the specific issues in the north. We are here for two days of hearings, and we will be going on to Moosonee as well. It was really important to all of the members of our committee that we do get that specific knowledge. I just want to reassure you that we are eager to learn and to take those matters into consideration.

Secondly, with respect to the issues that you've raised about staffing, costs and so on, we have heard about that before. It has been expressed to us also by some of the managers of some of the organizations. They're equally concerned about staffing levels and how they're going to be able to cope with things like paying pay equity out of existing budgets. There is a concern about that and making sure that both residents and staff are safe, so I appreciate you bringing that forward to us. It is something we definitely will be focusing on in our future deliberations in the committee.

1110

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: This is more a question for research again—sorry, Erica. Coming back to this wait-list issue: We've just heard that about a thousand people, one way or the other, in Thunder Bay alone, are waiting for services, whereas the ministry says there are 2,300 across all of Ontario. There were 4,500 who are in long-term care, so there's another 4,500. I would love to know what the total is of our presenters on wait-lists versus what the ministry says are on wait-lists. Clearly, there's a real problem there with getting actual figures. So I wanted to bring that forward.

Thank you for presenting. Thank you for what you do with so little—and that's what this committee is charged with doing. Clearly, the system, as it stands, is not working.

Miss Monique Taylor: Good morning. Thank you for the turnover. I know it's going to be a great snack at the perfect time of day.

This is excellent. You're talking exactly about what's happening, about the lack of resources, about the high turnover rates of staff and how hard it is to keep staff when they're underpaid and overworked. It's a very stressful environment.

What is the ratio in your home of clients to workers?

Mr. Brian Jacques: We have one to one, but—

Ms. Silvana Cacciatore: In the high needs—

Mr. Brian Jacques: In the high needs. But there are days when all three of us can't even support one person because he doesn't—

Miss Monique Taylor: Because the needs are so high.

Mr. Brian Jacques: Yes.

Miss Monique Taylor: It's so unfortunate. We're hoping that we will come up with the solutions for how to deal with matters like that, what needs to change to move forward.

Thank you so much for bringing your piece here and just being here and for the work that you do. I know it's hard work, and I know you do it for the right reasons.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: Thank you for your presentation today and the stories that you've shared. The reason we're out is to hear from people like you about how to make this system better, because we recognize that we need to improve. That is what we're here to do.

I want to let you know that the MPP for Thunder Bay will be joining the committee for tomorrow's set of hearings.

Like my colleague Ms. Elliott says, we are listening right across the province because we're looking to strengthen the system right across and coordinate across ministry areas.

I had an opportunity to visit with Community Living Toronto in my particular community in Scarborough. I went into the high-needs group homes, which require 24-hour specialized care, and just had a wonderful experience there. I also visited the respite programs for children and the day programs—and also hearing about how the network is supporting families and giving them resources

and support to be able to manage through various cycles in a child's and an adult's life. It's very important that we actually see. Hearing is important, but seeing is also important.

I fully respect the work that you do. Know that we are listening for ways of improving and strengthening this system of supports for people with developmental disabilities right across the province.

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Soo Wong: Thank you for sharing with us about the issue of workplace safety. I'm particularly interested to hear from all three of you, or one of you, in terms of best practices, from your professional experience. Can you share with the committee some of the best practices out there with respect to a facility like yours, and how do we improve that? Because your safety is our concern as well.

Mr. Brian Jacques: We're all trained in NVCI, which is non-violent crisis intervention. I'm actually one of the trainers. We have to have that to work in the workplace. But that can't prevent everything from happening. When I got my concussion, I was sitting there, talking to the one individual, comforting him because his mom had made a phone call and said that she wasn't coming to get him, and he was stressing about it. He got up and I got assaulted. It was nowhere near my fault, nor his; it was just the situation. But two staff on, compared to three, which there should have been, and now all of a sudden we have three staff? You have to wait until an accident happens. I mean, my injury could have been a lot worse than it was. Then what? It just gets put on the side burner: "Oh, we'll do better next time." No. Do better now. Don't wait for something bad to happen.

It's extremely frustrating because I see workplace injuries all the time, and it's sad. That shouldn't be happening.

Ms. Silvana Cacciatore: And it's very high. It is, I believe, 65%—

Mr. Brian Jacques: Sixty-five per cent of our staff at Community Living are on modified work. That's not right.

Ms. Silvana Cacciatore: Sixty-five per cent.

Ms. Soo Wong: Thank you very much for that.

I'll follow up with a staff question. Madam Chair, before we go to the next witness, can I ask the researcher, as part of the questions from the committee, can we get some data from the Ministry of Labour as pertains to reporting of injuries and accidents as relates to residential homes where workers are being assaulted or hurt, directly or indirectly? And do we have those data for the past five years?

What is the follow-up—because those homes should be inspected—and then what is the responsibility from the Ministry of Labour resulting from these inspections and following up with these cases? Because if I hear the number is 65%, where is the prevention? Where are the measures from the Ministry of Labour to deal with this sector? We know these workers are at risk. Furthermore, what strategies have been done to deal with it?

Also, the last piece here, Madam Chair, through you to the researcher, is the chief prevention officer. I want to know what is his responsibility to ensure this sector's workers are safe, because that's his mandate.

Okay? So thank you.

The Chair (Mrs. Laura Albanese): Yes, his mandate is in prevention; however, as they pointed out, we also have to look at standards that are not there right now.

Now that I've recomposed myself, I just want to thank you for your presentation once again, and for really pointing out the fact that there's not enough staff to meet the needs most of the time. Certainly, your safety is paramount as well. We need people like you to help in the sector. Thank you for the work that you do.

Just a reference for the various MPPs: Tomorrow, the MPP for Thunder Bay, Bill Mauro, will be joining us. He's in Toronto today. We've also been in contact with Michael Gravelle. And Friday, for example, we're going to Ottawa; we'll have Ottawa MPPs there. So they're joining us as we travel across the province.

Thank you very much for what you do every day. Thank you and keep safe.

MS. BRENDA PARRIS

The Chair (Mrs. Laura Albanese): Next we will be joined by Ms. Brenda Parris via teleconference.

Ms. Brenda Parris: Yes, indeed. Hello.

The Chair (Mrs. Laura Albanese): Hello. Good morning. How are you today?

Ms. Brenda Parris: Very well. Can you hear me?

The Chair (Mrs. Laura Albanese): Yes, we can hear you very well, thank you. Where are you calling us from?

Ms. Brenda Parris: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): Oh, from Toronto.

Ms. Brenda Parris: Yes, and I have lived in Ottawa for a number of years, so I know services in that area as well.

The Chair (Mrs. Laura Albanese): Excellent. You have up to 20 minutes to present to us today. If the presentation is any shorter, that will leave time for some questions.

Ms. Brenda Parris: Yes, I'm familiar. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. You may start any time.

Ms. Brenda Parris: I want to start by saying why I wanted to present to the committee. I've been following your work and reading the transcripts. My husband and I are adoptive parents of a young man, 27 years of age, with a developmental disability, who is on the autistic spectrum. Recently, through an accident in his group home, he has now acquired a spinal cord injury resulting in paralysis, so now we have a higher level of need for service and care. I've seen both sectors at play, the autism sector and developmental services, and I can comment on the differences and the tensions between them.

1120

I also want to present because I am one of the families that gave up custody of my child in order to receive services. This was the trend, as you know, a few years ago. My son became a crown ward in order to get residential help and treatment, so I know what it feels like to have your kid declared abandoned in order to get the services he desperately needs. I'm thinking here of Ms. Telford in the Ottawa area and other similar cases.

Unlike other families, I chose to keep my son in a stand-alone or segregated program in the school system, what is called in the Toronto school board a low-incidence school. Either he was in a special needs class or in an entire school devoted to their needs. In my case, it was Frank Oke; other parents, I know, have mentioned Beverley Street school etc. I did this not because I was opposed to integration, but I didn't feel the school board could adequately educate him and keep him safe in an integrated class setting, as our kids are often picked on, bullied and highly vulnerable in our modern high schools.

I also speak as a visible minority family—black Canadian—in a mixed-race family, dealing with the issues of race and racism in trying to get services in a sector that is uncomfortable and unwilling to incorporate cross-cultural understanding. As you can imagine, in large urban settings, this is increasingly an issue.

I speak as a professional—that's another hat I wear—social work administrator, executive director and a policy person in the former old office of the handicapped in the early 1980s. I was around for the changes in the system with the introduction of deinstitutionalization. So I understand the policy and program development over the years that we've seen. Sometimes I feel like we've been standing still for 30 years in terms of real, fundamental change, but I'll come back to that later.

And finally, I speak as a parent and as a mother. I'm active in parent groups on both sides of the spectrum, the autism groups and the developmental disability groups. I see a real difference in parent expectation and approaches in advocating for their children. I want to provide you with some truth about what happens on the ground and the practical realities day-to-day of these programs that we're talking about and often are touting.

Parents are often paralyzed and unable to think ahead, as they are struck at the level of sheer survival and fear for the future. We often feel abandoned and betrayed by agencies, by government and by our communities, communities that still persist in thinking that, in the phrase I use, "Doesn't the government take care of that?" You often have to hear that said when you talk to people.

I want to focus on just two issues identified in your mandate, because other people have spoken to other issues and I don't want to be repetitive. I want to speak about the range of housing and affordable housing options—I've been working with two parent groups trying to look at housing options for our young adults—and secondly, how the government should most appropriately meet these needs and provide these opportunities.

There are a couple of practical suggestions I'd like to offer.

First off, I want to offer an entirely different perspective in some thinking outside of the box, to ground my comments and to ground my solutions in a different paradigm, because I think we're stuck. I've read all the proceedings of your committee and other groups, and I've read some of the documents provided by the groups. I've heard the parents' voice in the wilderness, their desperation, and I've heard the usual self-defensive response of the government ministries and the agencies that deliver services.

The starting point for me is the usual linking of disability issues with welfare issues and, by extension, with a poverty, welfare mindset that shapes and delimits our responses to problems and their solutions. I contend that the major flaw in our way of thinking about these issues is the role of the welfare ministries as a lead ministry. Welfare and social assistance, which is the underpinning of the work of the ministry, is a minimal level of support. Welfare programs are discretionary, as said by some of the ministry presenters, and as such, not a mandated service or an entitlement service.

All decisions and plans based on an MCSS ministry model will only provide good-enough care, not the quality of care that parents want and need. These welfare levels of care will guarantee a life of poverty and economic and social disadvantage that we are continually trying, on the back end, to solve. Well, maybe we need to start looking at the front end.

As long as they always view our proposals and changes within this framework, we'll never really improve until we have a real philosophical change and transition in how we view these problems.

Many solutions are seen through a welfare lens. For example, when we talk about housing, it's always talked about in terms of public subsidized housing. There's no discussion about using the co-op model, where a group owns, or individual home ownership. Many, many parents that I meet and talk to all around the city and province are very scared of this option for their children, because they see, depending on the community you live in, some of the safety issues and drug issues in these communities, and they're terrified that their kid, if they're not going to end up in a nursing home, might end up in a subsidized environment where there are no supports to support them.

For example, many of the agencies are running group homes, what I call the new institutions. They take all the money from the clients and leave them with what we call the comfort allowance of \$135. I question why. Why do we do this? It guarantees poverty and continues the poverty framework. If you were to regularly rent housing in the community, say, in a rent-geared-to-income housing project, you'd only be paying around 30% of your income in rent. That's a huge difference in disposable dollars. Why do we do this? Because the welfare mentality is we don't want people to get ahead at our expense.

In terms of some of the presenters, they've been talking about inter-ministerial functions—a lot of discussion about this. It will always be problematic whenever you talk about inter-ministerial committees or solutions, because the operating principles are diametrically opposed. At MCSS and children's services, there's a welfare model, and that will prevail, so no wonder the Ministry of Municipal Affairs and Housing doesn't have a really specific response when you ask them to present to the disability issue. They view housing in terms of a principal, generic, open-access option, and they've devolved the authority to other people to do it, but they're not viewing it in the same sort of welfare mentality. I think that's going to be a continuing problem in any inter-ministerial solution you may suggest.

So I would suggest that we start with different principles and different paradigms, and that we accept that there are genuine differences in our needs, compared to other groups. I'm not saying that we're better or worse. I'm just saying there are genuine differences, and those differences I see as our fundamental vulnerability and dependency. These are constants. It's nothing to be ashamed about. It's not a bad, negative thing to talk about our vulnerability and dependency of our children. Our kids have lifelong needs that need to be fulfilled. We need a security of care for them and a certainty of continuity. That's what I maintain is different from other groups that may not have that lifelong need.

Secondly, I see it as an area of three-legged responsibility. I, as a parent, and my family have responsibilities, the government has responsibilities in the provision of supports and services, and our community has responsibilities to be accepting and welcoming of us. Our accident of fate should not destroy us or our family life. We'll assume our rightful but appropriate level of responsibility. It's not right that families should live in impoverishment, live in fear or worry, or bear the exclusive burden of responsibility.

Thirdly, I'd like us to switch to a model of mandated services, not discretionary. We seem to have lost, in the intervening years, our unique Canadian value of universality of service. These, to me, are very important principles that we used to believe in in Canada. We need universality of funding and universality of citizenship and participation.

Let's save the expense and pretense of pretending we're looking at eligibility with the DSOs. It's still the same model of basically excluding, or defining who's in and who's out. I would argue that we're all in, because as long as there's a particular need, it should be met in some appropriate manner.

These are difficult things to say sometimes, because everyone worries: "Well, does that mean there will be floodgates?" Not necessarily, but you have to start on the notion that universally, children with disabilities, who then become adults with disabilities, have needs that need to be met and should be met by our society.

1130

Fourthly, I'd like to increasingly transfer more of the roles to the Ministry of Health and Long-Term Care.

They're mandated to provide health services. I'm thinking particularly of the support services here. They're not discretionary in the way that welfare ministries are.

I think some services should be government-funded and government-run. Always devolving down to transfer payment agencies is a limited solution, and I think that we can do better than that. If we accept my argument about continuity and certainty of care, then some of that should be government-function-provided, consistently across the province. I'm thinking here of something like a service navigator role, because we continually hear about how parents don't know about things.

Not all parents are served by Community Living, and if you look at the numbers, they show that. I think your numbers show that there are 65,000 people, technically, with a developmental disability, but only 17,000 are receiving services. Well, what happened to the other 30-odd thousand? And, of course, they're increasingly growing in numbers with the autism group. So they're not being served, and they often are not the only people who can speak on behalf of parents.

Funding increases: I think it's a given. Everyone has been talking about the need for more money, and let's not tippytoe around that. When my son was in children's services, when he was a crown ward, the agency was paid \$320 a day for his level of need. As he approached 21, I was warned to expect an inferior level of service in the developmental sector, and I was told that, if lucky, they operate at something like \$90 per diem. Why we can justify going from \$320 to \$90 per diem is beyond me when the needs have not changed—of course, in his case they've increased because of the physical disability. So I think we have to accept as a given that there is a need for money and we need to find it. I think it's an appropriate request to make of our community and of society, and let's do it as wisely as possible, but I think we really need to understand that there needs to be more money in order to get better services and more services.

I would also like that that new funding not only be given to transfer payment agencies. Nothing will change unless attitudes and practices change, and I think we need to allow for some new innovation. I'd like the government to open up the list to other transfer payment groups, parent groups and community groups; allow the funding to develop micro-boards, which they use in British Columbia; and allow families to have funds transferred directly to them.

I know there has been discussion of direct funding; often the unions are concerned about it, because they see it as a devaluation of a public service role. I take a more balanced approach. I think direct funding can be used to good effect. It is used, in a sense, with Passport funding and Special Services at Home, but I'm suggesting that, even as people become adults, funding for their housing component could be given directly to families. Families can group into groups—micro-boards, which is what they're doing in BC—and can often combine services and funding.

Community Living itself, or agencies like it, are not the only advocate. They're often caught in a dilemma; I

call it the pact with the devil that they made. When the deinstitutionalization thrust happened, most of those people were transferred to group homes and Community Living or similar agencies. I think the big problem that these groups that were community advocates made is that they allowed themselves to become mere service deliverers. They allowed themselves to have a pact with the devil by accepting too little money for the people who were coming out of the institutions. They accepted these low rates of funding and the minimally enriched programs of care that that results in. I think this is unfortunate. When you ask for too little, you only get a percentage of too little every year. I think it was tactically a big error. For me, I do not view most of the transfer payment agencies as my advocate because of it. They are caught in the horns of a dilemma. They are service deliverers delivering programs that are increasingly poorly funded and poorly administered, and they can't get out of that rut.

I'd like to change that a bit by making funds available to new groups who can demonstrate their effectiveness and innovation and not shy away from giving money to new groups instead of the same consistent old gang.

I know direct funding—giving directly to families—is often stigmatized. There's often this underlying fear of the welfare mentality that I talked about. We're afraid to give money to people directly. But I think the UK experience and the BC experience can show us there are ways of doing this efficiently with the full accountability that you need whenever you do give money to anyone. I know the Ministry of Health is starting to do this. I would like to suggest—one of those low-hanging fruit suggestions—that we increase the funding for some of the attendant-care projects and increase the funding for the direct-funding projects that families are using, and let this happen even if you want to do it as a pilot project to demonstrate its effectiveness.

I'm coming to the end here. On the inter-ministerial discussion—I know there are lots of presentations on this—if you do anything in that as a solution, they need to have a clear mandate and a timeline and accountability. When housing and Comsoc and all the other people sit down at the table, there's no reason they can't do co-operative and collaborative arrangements: Housing can provide some funding and direction on the physical plant, and Comsoc and health can provide funding on the supportive service front.

This should be encouraged. Indeed, with the housing dollars, I suggest that the service administrators be instructed to come up with a plan with how they're going to meet the housing needs of this community.

Paramount is the need for the continuum of care and support, and in particular, family support for parents to help them deal with their fears, their pain, their panic and their worrying. My experience—and I've tried to work with parents on housing; I find they're unable to take steps due to the panic and the paralysis of worry and fear. If we knew that funding stayed with the person and travels with them and not with the program, and if we

knew there was some consistency, I think it would enable parents to step back and be able to think about future planning and not live just in the crisis of the moment.

I'll leave those points for you now. I will send this to you in written form. As you know, I was just informed at the end of the week last week that I would be speaking to you. It had been my intention to provide a written summary, so I'll make sure you get it. Thank you very much for this opportunity.

The Chair (Mrs. Laura Albanese): Well, thank you very much for your presentation. Unfortunately, we don't have any time left over for questions, but we do appreciate your suggestions and your input into the process. Thank you very much and have a great day.

Ms. Brenda Parris: Thank you. I do note that other groups were given 30 minutes, so if there are any questions any of your members have, I'm happy to—

The Chair (Mrs. Laura Albanese): Only ministries were given 30 minutes. Every other presenter has been given 20 minutes.

Ms. Brenda Parris: Oh, okay.

The Chair (Mrs. Laura Albanese): Yes, okay. Thank you very much.

Ms. Brenda Parris: Thank you.

ONTARIO ASSOCIATION OF RESIDENCES TREATING YOUTH PARTNERS IN PARENTING

The Chair (Mrs. Laura Albanese): We'll now be joined by the Ontario Association of Residences Treating Youth, OARTY, and specifically by Rebecca Harris. Hello?

Ms. Christine Rondeau: Hello. Actually, it's Christine Rondeau, on behalf of OARTY.

The Chair (Mrs. Laura Albanese): Yes, good morning.

Ms. Christine Rondeau: Good morning.

The Chair (Mrs. Laura Albanese): Where are you calling us from?

Ms. Christine Rondeau: I'm calling from Ottawa.

The Chair (Mrs. Laura Albanese): Oh, from Ottawa? That's great. Your name, again?

Ms. Christine Rondeau: My name is Christine Rondeau.

The Chair (Mrs. Laura Albanese): Christine Rondeau. You have about 20 minutes for your presentation to the committee. You may start at any point in time.

Ms. Christine Rondeau: Excellent, great. Thank you so much. Thank you for inviting OARTY to this important information-gathering. OARTY is the Ontario Association of Residences Treating Youth. I'm speaking today on behalf of OARTY but also on behalf of my own company, which is Partners in Parenting in Ottawa, as well as a parent of a special-needs child. So I'm coming at you from three levels.

OARTY is a provincial association that represents 70 member agencies that provide private residential care and

treatment to approximately 3,000 children, youth and adults on a daily basis.

A significant number of our clients are in the DS sector, and OARTY continues to work with your ministry. We started off with the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, and we did a presentation there. But we're also continuing to work on developmental services day to day and, more significantly, working with the agencies that can provide service to people in need.

1140

OARTY members are very eager to work with government in order to help create an Ontario where individuals have the best opportunities to succeed and reach their full potential based on person-centred planning, and the freedom of choice and individualized funding comes into that for sure.

The ministry emphasizes flexible services. That is one of our hopes, that people—individuals, parents, families—will be provided with a full choice of services that are available within Ontario. Right now, the system tends to work through a transfer payment system, and the transfer payment systems dictate or create the spaces for individuals with special needs to reside. Ideally, there would be a more fluid system, one that could offer a choice to families and individuals as well as one that can offer the right support to the client and create more fulfilling environments for individuals to live as opposed to just living in a group home that they're plunked into because that's the only space available.

The way it sits right now, and from our hands on in the private sector, we support many, many individuals with developmental disabilities mainly starting from children—children who have come through the child welfare system and children who grow up in the system, and then, at age 18, get moved from that system into the adult system. Typically, the children who come through the child welfare system are the lucky ones. They are the ones who get support right through their lives. The children who remain at home with their families that don't have those supports—they end up with the burden in the end, where their child is now perhaps 18, 19, 20, their other children are leaving, and their child with special needs has no options or minimal options. Again, it depends where in Ontario you reside because things are different across the province.

One of my pieces is to look at how we streamline things across the province so that they are more effective. I know with the development of the developmental service agencies, the DSOs, that the goal there was to improve streamlining into the system for adults. But from my perspective, it has just created another layer of bureaucracy and another layer of frustration for families and parents on two fronts. One, there's the process, which is great; there's actually an entry point to the system, except families then feel like there should be the next step, which means money allocated to their child so that they can continue to have support.

Going back to what we do in the private sector, the private sector offers high-quality treatment in residential

care at a cost-effective price point, a clear understanding that OARTY is a part of the system. Although we're not a TPA and we're not incorporating as part of the system—incorporating it as part of the system will enable the government to treat considerably more adults with the same investment. So because our system operates differently than a transfer payment system, we can provide care to more people, with less money going out to infrastructure and more money going to the person.

The private sector has open spaces. When we hear that there are waiting lists, it really makes us cringe. When I get families calling me saying, "Do you have a space in your home?" and I say, "Yes," and they say, "We've been told that there's a five-year waiting list," or an eight-year waiting list, "How do I get my child into your system?"—there's no easy answer to that.

Some families can advocate, and some families have the ability to be the squeaky wheel, which is, from my perspective, what DSO was supposed to remove. But it's still occurring on the ground floor. Families who are connected or understand the system have the ease of access of getting their child service.

Another point that's pretty significant is there are a significant amount of individuals who are in hospital—dual-diagnosis clients, clients with medical needs—who are bogging down the health system. I feel that there need to be better relationships across the board from the Ministry of Health, the Ministry of Community and Social Services, the Ministry of Children and Youth Services, as well as the Ministry of Education.

When children are born with special needs, it needs to start at that moment. Systems need to be established at that moment for families so that throughout the youth's life, there is a support network in place. Right now, the system is not there, but as it continues to grow, the system needs to be better managed with all the ministries that are involved and all the ministries that touch. Children are born in a hospital. It starts with the medical and then jumps to education very quickly, and then in there comes the child and youth services, and children become adults. So it needs to be a continuum and a coordinated effort.

Going to the families of children with special needs: I see a lot of families, because we provide foster care and residential and day supports to adults with developmental disabilities. So we see a lot of families when they come into the system and they are burnt. They're in crisis. They need support.

I think if an infrastructure is built that can provide support throughout, similar to what currently is happening with Special Services at Home—although that system has some flaws, but it's a good start—where families are provided with dollars to support their children, it can continue to grow. There needs to be a better collaboration across the board, in terms of hospitals, in terms of schools, but starting with providing the family support. That's an obvious need. I see depressed and defeated parents who are so desperate for support, so trying to fight the system, that they need action.

Differences across the province are sometimes difficult to swallow, let's say. Here in Ottawa, we have quite a good system in terms of the private system working directly with a transfer payment system that contracts the private sector to provide support because there aren't enough transfer payment agencies or the transfer payment agencies perhaps aren't as flexible in providing care to the dual-diagnosis or the complex-special-needs children, youth and adults.

1150

The model that we have in Ottawa is one that is an anomaly across the province. Working at the provincial level through OARTY, I see that there are not a lot of opportunities for the private system in other regions, but I think that is something the government should look at, and it should look at how we can tap the unused beds that are there and how we can have the private operators create a system that is not built on infrastructure but is built on individual needs of the client.

Just an actual example of that—you know, there are some really neat things happening in the system with individualized funding. Most recently, we've had a youth who just recently turned 18 and has complex-special-needs funding. He's not from the Ottawa area but from one of the local counties surrounding Ottawa. His parents were working with an agency that provided a week on and a week off support while he was a child.

Two things occurred for this young man. The program that he was in was a children's program, and on his 18th birthday they cut support. He can no longer go to this children's program where he was getting a week on and a week off support. The TPA-funded program was not successful and closed their bed, moving from a large nine-bed home to a small three-bed respite home.

The family themselves needed a full-time placement for their youth, so the supporting agency contacted Partners in Parenting to see if we had any vacancies. We did, we had a vacancy, and we matched the space for the youth toward the family, got to know the youth, and started a transition plan, all within a month of the first phone call. Now this young man has a full-time placement where he's matched with age-appropriate peers.

We have a three-way agreement between the community agency, the parents and Partners in Parenting, even so far as the parents themselves receiving funding from the agency, and they pay directly for the child's residential care. This is happening now in two of our cases, where the parent pays directly with funds that they receive from their transfer payment agency.

The family is involved; they have choice. They were able to decorate their child's room. They work closely with us. We're trying to get this young man into school, because he's been out of school for the last two years.

Government and community agencies need to change their philosophy about families and start working with them on creating opportunities and not continue to fund transfer payments solely based on infrastructure but actually look at the need to decrease the waiting lists that are out there and decrease the community pressures: not

just the people who are waving their hands, but the people who have been on the waiting lists for five, six, seven, eight, 10 years. I think in all of the years that I've been working directly with families, I have only seen two clients who have been at our day program actually get a transfer payment spot—two community clients in all of these years. It is so rare that somebody off the community list actually gets housing support. Families are urgently requiring the support before they drop their children off at hospitals, before they drop their children off at developmental service agencies.

The other piece I need to mention is that there is no entry point for children into the system. For over 18, it's Developmental Services Ontario. We can understand the system. Prior to your 18th birthday, there is not an entry point. In the past, it had been the children's aid society that would look at agreements with families to provide support and care, but that was taken away years ago. Now, at this point, if a family requires support, there are hoops that they have to jump through—not just one but multiple; many years and years and years of hoops—to try and get their child identified for some additional supports, let alone to be brought into some kind of a residential support system. There needs to be the creation of an entry point for a child who is identified at birth right through the system so that families can understand what the system is and know the expectation and know the limitations of the system, so that they can plan with external supports, right?

I know we often hear that the system is saturated. Absolutely it is, but the funding is not being brought down to the lowest level, which is the child or the individual who requires the support. The funding is going to support agencies. The funding is going to support middle levels and agencies, but what we need is the actual on-the-ground programs that will provide the supports to children, to babies, to youth.

There are cases of children sitting in Sick Children's Hospital for years and years and years who—we have presented to take that child with the right support. It would have meant that there would have had to be an agreement with the Ministry of Health and an agreement with the Ministry of Community and Social Services, but boy, that's really hard, to get all the players at the same table looking at one child. In the end, children stay in hospital, and people with dual diagnosis stay in hospital, even though private sector agencies have beds available. When you look at the cost of health versus the cost of residential care, you're talking minimum \$1,200 to \$1,500 a day—minimum—in a hospital setting, and you're talking maybe \$250 to \$300 a day in a private residential care facility that would provide that person with all of the daily care needs that they required, including additional staffing that hospitals cannot provide.

The biggest piece that I bring to this is that individualized funding is essential. Families need to be identified early, and support needs to be an integral part of having a special-needs child. My husband and I adopted a little girl with cerebral palsy. At the age of two, she requires

physical care. She requires all sorts of special equipment. We get a minimal amount of money from Special Services at Home, which is great, and we use every single penny to make sure that she has independence in the community like any other child. Building on that to the next level is really important. Being able to know that when she's 18—she's now 10—and an adult, what is the next step? At 21, she's out of school. What is the next step? Where does the Ministry of Health fit in? Where does the Ministry of Education fit in?

Collaboration is vital for success, and making sure the funding is there, almost attached, when a child is born, and used appropriately for the child's care, not used to build infrastructure around transfer payment agencies and mid-level agencies. Focusing on supporting families and creating resources for families is vital.

In conclusion, OARTY would like to continue to work with the Ministry of Community and Social Services and the Ministry of Children and Youth Services to ensure a seamless transition for children from children's residential care to adult services. We believe that together we can create a holistic, seamless, cost-effective system for adults and children in the developmental services system. The private sector is ready, willing and able to support clients and willing to expand services to continue to support adults.

1200

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Christine Rondeau: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation, Ms. Rondeau. It was quite comprehensive. And thank you very much for adding your voice to the process that our committee is going through. Thank you so much. Bye-bye.

Ms. Christine Rondeau: Thank you. Bye-bye.

The Chair (Mrs. Laura Albanese): We are recessed until—

Ms. Sylvia Jones: Can I ask one research question?

The Chair (Mrs. Laura Albanese): One research question.

Ms. Sylvia Jones: The previous presenter, Brenda Parris, from Toronto, made reference to micro-boards in BC. It's a family housing model. I wonder if we could get a little more detail on how they're doing that.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Yes, and on that same note, the UK model has been mentioned, and the Australian model. It would be interesting to know what they do.

The Chair (Mrs. Laura Albanese): Ms. Elliott.

Mrs. Christine Elliott: I have one further question; several of the earlier presenters were speaking about it. I think it was Mr. Mick Kitor who was speaking about the process for getting your child into an autism program, and the discharge criteria and the review mechanism. I was wondering if we could get some more information about exactly how that all works. I'd like to understand that better.

Interjection: Not very well.

Mrs. Christine Elliott: Apparently not, but I'd like to know a bit more about that.

The Chair (Mrs. Laura Albanese): Please finish, Ms. Elliott.

Mrs. Christine Elliott: No, that's fine.

The Chair (Mrs. Laura Albanese): Okay. Ms. Taylor?

Miss Monique Taylor: I would also like some information back about PPM 140. We were hearing quite a bit about that this morning. It doesn't seem like it's actually being implemented as it's supposed to be, so some information back on that would be great. Thank you.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: Thank you very much, Madam Chair. With regard to next week, I believe we are hearing in Toronto Monday and Tuesday.

The Chair (Mrs. Laura Albanese): Yes, we are.

Ms. Soo Wong: I want to ask a question through you to the staff. Do we have space, either Monday or Tuesday, to invite—yesterday, we heard a lot about concerns dealing with families with FASD. We have experts at St. Mike's hospital, as we heard yesterday, as well as at the Hospital for Sick Children. Is there room on either Monday or Tuesday to invite these experts, who are in our backyard, to hear about FASD? We really have not heard from the Hospital for Sick Children and St. Mike's. One of the witnesses talked about a St. Mike's program. I want to ask that question, Madam Chair, through you to the staff about next Monday's and Tuesday's schedule.

The Chair (Mrs. Laura Albanese): Do we have room?

The Clerk of the Committee (Mr. Trevor Day): As it stands now, Toronto is being scheduled as we speak. We have 42 spots available over that time. We've asked for a third of those spots from each of the parties, and your selections are being contacted right now and asked if they can appear.

If you would like to invite someone specifically in for a period of time, it will reduce one of your selections or three of your selections, depending on the time. It would be something that is up to the committee to determine, if they'd like to pull off one of their selections, or a portion of time, and replace it with, in this case, an invitee for the committee.

Ms. Soo Wong: Okay.

The Chair (Mrs. Laura Albanese): Would we have time to invite them—we can't meet again—when once we finish the hearings, we're not allowed to meet until the House resumes?

The Clerk of the Committee (Mr. Trevor Day): That's correct. The committee will have used up the days allotted to it by the House.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: I would just suggest to Ms. Wong that maybe you use those as a couple of your picks.

Ms. Soo Wong: Okay. Well, my other comment, Madam Chair, is that if that's the case, we can rewrite. If

there's no time allowance, I have to see what our picks are.

With respect to the issue of FASD, we consistently heard concern about FASD yesterday, so if we could write to St. Mike's and the Hospital for Sick Children.

I also know—and I think one of the witnesses yesterday also commented—about children in care who are currently with FASD. There are experts, there are agencies, currently in Ontario that could shed some light and provide some best practices to this committee. I think it would be due diligence for this committee to hear from these people, whether in person or in writing to this group.

So I will follow up, Madam Chair, with the researcher—I have to look at the list—and then the second piece is to get some written submissions from these experts. I just wanted to note that on the record.

The Chair (Mrs. Laura Albanese): Yes, Ms. Elliott.

Mrs. Christine Elliott: Just another possible consideration with respect to that. I know we have a deadline for the submission of our interim report, but we will have another opportunity following that to investigate any other topics that we think need to be followed up on. So that might be an opportunity post-February 19 to call some witnesses in, to see if they'll come and speak to us to answer some of the additional questions that we have.

The Chair (Mrs. Laura Albanese): Okay. Ms. Hunter?

Ms. Mitzie Hunter: One of the questions, the first time I heard it in listening to all of the presenters, was on the issue of race and racism and getting the sector to be responsive in a cross-cultural way. I hadn't heard that before; it has not been raised. So I don't know how we explore that—maybe getting back to Brenda Parris, because it was something that she made as a comment. But I have noted that, because it was the first time that it's been raised for us.

The Chair (Mrs. Laura Albanese): Okay. We'll adjourn for lunch, and we'll continue to discuss later. We'll be back at 1 p.m. in this room.

The committee recessed from 1206 to 1303.

MS. CINDY WALKER

The Chair (Mrs. Laura Albanese): The committee is resuming its session.

Good afternoon, Cindy Walker; thank you for being with us today and for adding your voice to the work of this committee. You may begin anytime you feel ready. You have up to 20 minutes for your presentation. If it should be shorter, then we'll divide the time equally amongst the parties for questions. Thank you.

Ms. Cindy Walker: Committee Chair, committee vice-chair and honourable members of Parliament, I would like to thank you for the opportunity to address the committee. My name is Cindy Walker, and I am here today with many different perspectives. Formally, I have had roles in the health care field, specifically in complex continuing care, acute care and long-term care, as well as

roles in post-secondary education. Today, however, I speak to you as a mother, advocate and legal guardian of Jeremy Walker. I must say it is very hard to present a life in such a short time frame. As I talk, I will also be a voice for my son Jeremy, my husband Ron, our son Daryl and our daughter Crystal—they happen to be in the audience there, Daryl and my daughter Crystal.

Our son and brother, Jeremy, is 36 years old. Jeremy lives in an apartment in the front of our home. My story is not unlike others you may have heard or will hear in the next few days. I am sure, though, that themes will be similar. Jeremy was born in an era where autism was rarely heard of and poorly understood. Jeremy's pre-school years were filled with many questions as to why he was the way he was. Many specialists and experts were involved. Over the years, these individuals could not understand or describe why our little boy behaved this way.

When Jeremy entered school, the questions continued. However, formal testing would not begin until he was eight years of age. During this time, speech therapy was started, and we were told perhaps we were dealing with dyslexia. Our boy was different, but we managed as we could. It was not until he entered adolescence and needed to move to a secondary educational facility that we were required to have more expert and specialists involved.

My husband and Jeremy's siblings loved Jeremy as he was. We were led to believe he was mentally delayed and accepted him as such. Yet the school system did not understand his behaviours and demanded further testing. We were referred to a short-term assessment and treatment centre. Jeremy failed miserably; he required same-ness, and he didn't follow the direction given to him to attend programs. This led to physical restraint, and he regressed and did not respond at all. No one knew what to do and what was wrong with our Jeremy.

At the age of 15 years old, Jeremy moved to an adult psychiatric facility. It was during this time that chemical therapy was started. We were not allowed to let Jeremy be as he was, as we were informed he had a "major psychiatric condition and he was in need of treatment." I was told I was in denial and my son "would need medications for the rest of his life." During his treatment, Jeremy became very ill. He suffered from neuroleptic malignant syndrome, precipitated from his treatment medications. Sometime into his treatment, he developed a tardive dyskinesia. I was told this condition may never go away. Fortunately, it did over time.

I brought him to London, Ontario, for further assessment and, to my dismay, more chemotherapy was started. At this time, I was told he would not be able to go home as he was too ill. I did not believe this so I brought Jeremy home. He was 17 years old. He suffered from medication-induced delirium, and it was at this time, after numerous diagnoses and chemotherapy to accompany the diagnoses, that I decided to discontinue Jeremy's prescribed treatment, as it was putting his life and well-being in jeopardy.

At the end of his 17th year, Jeremy was diagnosed with autism. I was introduced to Wesway, a respite

agency. At the age of 18, Jeremy wanted to become independent and live away from home. He moved to a one-bedroom apartment. We had some supports in place for him through the Wesway agency, but this proved to be inadequate. After another trial in a small one-bedroom house failed, Jeremy moved back to the family home.

We moved with Jeremy to the country, where we reside today. Our family was in need of more support at home. I was told I was at the maximum number of hours and this would not be possible. Our son was growing up and difficult to handle in the community. Our younger son Daryl was 16 years old at the time. Being a young male, he was in charge of running after his brother. Not unlike other autistic young men, Jeremy would walk and run for miles. He had no concept of time or distance. However, he could not find his way back home and would get lost frequently. We feared for his safety in the community, but the worst fear was being in an institution, medicated and restrained. This was no life for a young adult. We were in need of help.

When Jeremy was 19 years old, we were told about a pilot project, called the Choices Project. When I called to ask about the project, I was informed that the pilot was over and if I wanted in, I was to find someone who already had funding in the project. After months of advocating and many letters and phone calls, I was told we were able to have some funding to hire staff to look after Jeremy at home. We were excited to have some funding to pay the staff. We were happy to be able to do a shared-care arrangement, where we would be part of Jeremy's life but could hire the staff we needed to keep him safe and secure. I wish I could stop here and tell you how wonderful things were, yet I need to continue.

1310

More assessments were required, and the experts and specialists came, once again, to our home. Many questions followed. When I asked why we were being assessed again and again, I was told, "Things change, and Jeremy may get better with the proper treatment." We needed to explain our story over and over again. Our story about requesting supports is lengthy. I can tell you, though, that it was and is a demoralizing process. The process was and is humiliating to our family. The inadequate funding was harmful to all of us in the family.

Jeremy's brother, Daryl, requested to speak to a representative of the Ministry of Community and Social Services. He was not able to continue his high school education, as he was helping our family care for Jeremy. He was not able to talk to anyone. The door of communication was closed to him.

A few years ago, we were required to have a team of behavioural specialists in our home in order to maintain our funding. Medications were offered once again—the same medications that were trialled with disastrous results in the past. Once again, I had to explain what had happened, and I was told, "It may not happen again in another trial." This time, I held my ground and I refused. I requested proper experts from the Geneva Centre.

It is important to note that my funding was always in jeopardy if I didn't open my home to whomever the

Ministry of Community and Social Services wanted to send in.

"Creative options" is a term frequently and continuously used by MCSS. I was once told of a creative option by a Lutheran Community Care Centre program manager. She proposed that we build a cage outside my son's apartment door to save money for overnight staff. She wanted it high enough so he couldn't climb over top of it and locked to keep him in. I am saddened.

One time, I asked how much money it would cost to look after Jeremy elsewhere; I was shocked to hear three to four times the amount that we were funded at the time.

The system wanted us to explain over and over again, year after year, just what Jeremy's behaviours were, to look at strategies to cut his support costs down.

Fortunately, for years, we had a planner who listened to our story and fought as much as she could, telling our story and advocating for us. Now this planner has left, and we begin a new journey with a new specialized support coordinator. In a recent communication regarding funding renewal, this support coordinator stated, "I am open to sitting down with you and/or Cindy to discuss and brainstorm other ways to save or look at low-cost/no-cost service to add to your team of supports," and, in another communication, "I am available to assist with planning for other resources and supports creatively." We are back to square one.

I'm going to do an add-on here that's not documented in this paper. We have done creative options since this little boy was born, to the point where we are in severe debt. When we didn't have the proper funding, we needed to keep him out of the psychiatric institution because he was at risk, so we took him out of there and we had to support him. I couldn't work; I had to stay at home. It took two of us, because he was such a challenge. To support the family, we had to keep on going back to school to live off of OSAP. I went to school for another five to six years. I have three degrees now, but I also owe a lot of money. We did that until I was able to advocate for the supports that I have now, which enabled me to start working again in 1999. That's when I started work again. So I just needed to talk about the creative options that we have done and what it's done to our family.

As I was saying, we are back to square one. It is funding negotiation time. My husband, Ron, developed a new budget to include WSIB increases as well as a wage increase for staff that are making many dollars less an hour than any other agency in the city. Responding correspondence from a representative of MCSS replied that IF budgets have been frozen and increases have not been accepted. We have been informed that there is no appeal process. I have that correspondence if you're interested. My husband and I are always on edge at this time of year: There is never a guarantee of funding for Jeremy. Our son will be as he is, and no amount of medication or treatment will change that. Why is there always the need to fight for and justify our funding every year? We feel we have developed a very cost-effective and innovative model of support for our son.

The following are our recommendations:

- facilitation, coordination and integration of health services in the community for individuals with developmental disabilities;

- development of a community outreach program to ensure timely access to service for those who have a developmental disability

- development of a system to monitor needs of informal caregivers of those with developmental disability;

- recognition of families who choose to develop and maintain innovative models to keep their loved ones supported in a home environment;

- support for the informal caregiver when they take on the role of coordinating services in the home;

- funding should be directed into the health care system to train hospital personnel. It is very, very difficult for persons with developmental disabilities to get the proper medical care—very difficult;

- the Ministry of Community and Social Services should be more welcoming of families, in particular siblings, that want to share their stories. There should be more of an open-door policy;

- more funding into emergency respite for siblings assisting with family members with disabilities;

- access to grants and bursaries for siblings that live with a family member with a developmental disability; and

- continuation of individualized funding for residential supports so more unique innovative models can be developed by families.

I have given a brief overview of my family's journey through developing systems. It is my hope that others will learn from these experiences and not have to go through the same pain and suffering as my family had to. I look forward to a more receptive partnering of families and the service system. To this day, my family and I continue to be challenged on support decisions as opposed to partnering together to nurture our gifts, strengths and contributions. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you for sharing with us the difficult times that your family has endured. Thank you for your courage, for not giving up and still fighting for Jeremy. We have only about a minute for each party to comment. Miss Taylor, I'm picking up where we left off in the morning.

Miss Monique Taylor: We don't have a lot of time. Thank you for being brave enough to come here to speak to us today and for sharing your story with us. Your life is hard enough already, and to come and have to spell that out to us is not an easy thing to do. We appreciate your time and your energy for being here today.

Ms. Cindy Walker: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: I also want to say thank you so much for your openness and sharing your story. Our goal here, what we're trying to do, is to put together a series of recommendations that will help improve the system for individuals with developmental needs and to ensure that there is a coordinated system of supports across their

lifetime. I want to thank you for sharing your story and Jeremy's story with us today.

Ms. Cindy Walker: Thank you.

1320

The Chair (Mrs. Laura Albanese): Ms. Elliott?

Mrs. Christine Elliott: I too would like to thank you very much, Ms. Walker, for being here today. We know that this isn't easy for you, to share your family's story. All I can say is that we appreciate the fact that you took the time to be here, and that we take your concerns very seriously. We know that families like yours are exhausted and stressed beyond measure. We want to do something meaningful at the end of all of this to make your lives easier and to allow your son, in your case, to have a happy and productive life.

Ms. Cindy Walker: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much.

MS. MARILYN LEITERMAN

The Chair (Mrs. Laura Albanese): And now, we call on Marilyn Leiterman to come forward. Good afternoon.

Yes, Ms. Wong?

Ms. Soo Wong: Madam Chair, just before we have the next witness speak: Given the recommendation from this witness about the siblings issue and support, can we ask staff to get some data from MCSS with respect to funding and support for siblings, and what the resources allocated to families with siblings are? Because this is the first we've heard of this concern.

The Chair (Mrs. Laura Albanese): Yes, okay.

Ms. Soo Wong: Let's get some data.

The Chair (Mrs. Laura Albanese): Thank you. Welcome. You'll have 20 minutes for your presentation this afternoon. Should it be shorter, that would allow for some questions from the committee members. You may begin any time.

Ms. Marilyn Leiterman: Thank you, Chair and assembly. Thank you for this opportunity to be here. We had discussed whether I should bring a presentation etc., but for well over a decade I've been dealing with the issues I'm about to discuss, so I'm quite well-versed on it.

I am a parent of five children. Three of them are my foster children and two are bio. Four have disabilities, including FASD, ADHD, ODD, ARND and the gamut—the gamut is large. Through necessity, over a decade ago, I was given this little child and he was undiagnosed with FASD—fetal alcohol spectrum disorder.

Through necessity, and in finding ways to support this child, I went to college. I had to go back to school, and I took FASD education through Alberta. I've really had to learn a lot about this disability. To date, FASD is the most misunderstood and most undiagnosed disability across the board. I spend days, weeks and months 24/7 within the field of FASD, supporting parents online,

creating parents' groups and support groups, and working with support groups.

We still struggle. This is northern Ontario, and a lot of people consider northern Ontario separate from southern Ontario, as sort of another province. We find that there's a lot of difficulty with supports for FASD.

My child is now in grade 4. He still has trouble with the stress of school and understanding what's expected of him. It's very common in persons with FASD to have poor memory, poor cognitive skills and lack of cause and effect, which is learning from their mistakes. He continues to struggle. To get him supports in school—I'm lucky enough, and I say this almost tongue-in-cheek, that my son goes to school with someone with autism. The child with autism has support, so he's able to piggyback with this child.

My son's issues are profound. He is diagnosed with a mild intellectual disability because, just this year, as many of you know, FASD was put within the DSM-5—finally; we've been fighting for that forever.

What I'm looking for here, I guess—I mean, there are many things, but what I see working within a social service field and working with people within it is that these children are misdiagnosed and misunderstood. They don't get the support that they need in school to understand their disability. They're very vulnerable to being bullied and vulnerable to being influenced by others. They very often have poor math and reading skills; they do okay in the first couple of grades and they start falling back, and the gap keeps widening on their education, so they start losing self-confidence.

Then they get into trouble within school, acting out and behaviours, because they'd rather be seen as a bad child than as a dumb child.

Unfortunately, with this disability—I mean, the real definition of FASD is mental retardation in many cases. The IQ under 70 very often happens. But sometimes it doesn't, and I think that's partly where we misdiagnose: if someone has a fairly high IQ, if they come across as well-spoken, they come across that they are understanding what's asked of them, and they actually aren't. They're not understanding a lot of it.

So what I see and what I have parents contacting me about is that the child quits school, leaves school, gets into gangs, drugs etc., and then they are in jail. As many of you know, there's all kinds of literature on the high numbers of persons with fetal alcohol spectrum disorder in jail. We need to stop this. We need programs that have vocational skills.

My children are very talented. However, they are not going to be intellectuals; they're not going to be academics. They are very skilled vocationally. All of them want to be part of society. They want to learn. We need programs in vocations. We need protection factors put in here. Like the lady was speaking about with her child with autism, the same goes with FASD. I do not want a cage for my children. I want help for them. I want programs where we can work together and help them succeed and where all can be part of society and contribute to society.

My son, the youngest, will struggle throughout his school life. The gap in grade 4 is already increasing tremendously, so his self-confidence level is really starting to sway. And it's weighing on him. He knows he's a little older than the other kids. He knows he can't learn the same as them.

I became an FASD educator. I had to learn about sensory integration. All of these issues affect the brain. We need changes within the physical part of schools etc. A lot of kids can't handle sight, sound; different stimulations affect them. They are not able to focus and study. There are all kinds of things that we can do to help children with FASD.

One of the biggest challenges is that we know that one in 100 will be diagnosed formally with FASD. That leaves about six who will never be diagnosed. They're still struggling with school. People look at them like they're the bad kid, the kid who just doesn't get it, the kid who doesn't care, the kid who doesn't want to participate. Here, they can't handle it. They will never be diagnosed. If they don't have the facial features, if they don't have disclosure from the parents, they will never be diagnosed. However, going into schools and speaking to teachers, there are two to three children within every single classroom who have some issues, undiagnosed issues that need to be addressed for the success of these children. We want success; we're looking for success. We want to work together to find a way, first of all, to prevent FASD, but for those who are affected, we need some programs to help them. It's easy to say, "Okay, I want supports. Okay, I want programs," but we need to discuss at length what those programs could look like, what they would be for their support.

I welcome any questions because, like I said, I've been doing this for so long that I have thousands of things swimming in my head and I might miss some pertinent things that you guys want to know or hear.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. We have about four minutes for each party and we'll go in rotation. Ms. Wong?

Ms. Soo Wong: Thank you very much for sharing your family's story and particularly your advocacy work for that many years. We certainly heard you.

Now, can you share with the committee, with regard to your school board, what they are doing to support your child from the time your child was diagnosed with FASD?

Ms. Marilyn Leiterman: Sadly, FASD is not in the criteria for exceptionalities, so I'm going into the school and saying, "Here's this invisible disability. Help my child," and I'm getting, "Oh, well, we can only assess two children per year per school because of funding." My son was lucky enough that he had enough difficulties, so by seven years, by grade 2, they assessed him.

I had to be the strength, the advocate, from day one every single year. Three of the boys are going to school and are still struggling. Every single year, I have to go back into the school, address the issues with my children, seek out the new teachers and explain their issues with the teacher in order for them to be helped.

1330

Ms. Soo Wong: My next question is, at the school board level, are you part of the SEAC committee, where you can advocate for system-wide support not just for your family but for others?

Ms. Marilyn Leiterman: I have been in the past. I have some very good friends that are in it. Because of all the work that I do, I had to step back from SEAC.

Now, while I was in it—I mean, they are very creative. The boards are getting creative with working with children with these issues. My problem is, let's diagnose it for what it is. Let's recognize the issue, and let's listen to the parent, because the parent knows. The parent is always pushed to the back of the issue. All the professionals know better and know more—it's the parent that knows. If you have a parent coming in and saying there's something with this child they need help with, then they need help, and that's it.

Ms. Soo Wong: My last question is, in your school board, are parents able to participate and be members of the SEAC committee? Because we heard that parents are not invited members unless they belong to an organized group. I just want to know, from your experience at your current school board here in Thunder Bay, can you or other parents be active members of SEAC?

Ms. Marilyn Leiterman: I have a gentleman here from SEAC. I can ask him directly, because it has been a while. David?

Mr. David Fulton: No, it's an appointment by organization.

Ms. Soo Wong: Okay, so it's by appointment for the Thunder Bay District School Board. Am I hearing that? Okay, thank you very much.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Wong. We'll pass it to Ms. Jones.

Ms. Sylvia Jones: Thank you, Chair. Thank you, Marilyn. You mentioned that you are an FASD educator. I'm hoping you can help me with this: In terms of the school involvement, the school side of it—obviously, one of the things I'm hearing you say is you would like FASD to be considered one of the exceptionalities. Is that right?

Ms. Marilyn Leiterman: Absolutely.

Ms. Sylvia Jones: Okay. What are some other fixes or recommendations that we should be looking at, at the school level?

Ms. Marilyn Leiterman: Well, number one, from the time this child was three—in JK, I was going in, and I would bring sheets into the school to cover up things so that it wouldn't be so distracting for him, so he could learn.

One of their newest policies is to have all work, say, shown on the walls—everything up. We know that children with autism, FASD, Asperger's and many of these disabilities cannot handle overstimulation. They need things calmed down.

If the policy is written by the board, that seems to be it. It's extremely difficult to get in and work for change of any kind that would be beneficial. We've found, with

going in and training in different areas, that what benefits one benefits all. If it's a better study atmosphere, then it's better for all.

There just seems to be—it's extremely difficult to get any change, to be listened to. I'm a professional in this field, and it's still difficult, you know?

Ms. Sylvia Jones: Do I understand it correctly that your children have always been part of the regular stream? There's no separate classroom that they've—

Ms. Marilyn Leiterman: No. The thing with fetal alcohol syndrome is that it's almost a cruel disability in some ways, because there's a lot of intellect going on. However, for the child to bring forth the knowledge and display what they know—it's often stuck up in the brain.

For instance, two of my three boys know they're different, but they sure don't want to be in that crowd of kids that look different. They absolutely do not want to look different. Like I was saying earlier, my son who's one year older than the rest of his classroom is super hyper-aware that he's older, and he does not want to stand out for any reason. These children are hypersensitive to ridicule.

We have a lot of information on school shootings etc., of the children, and the background can have FASD. They've been challenged. They've been pushed to their limit. They feel rejected. They feel like they're not part of society and no one understands them and no one cares. They're just very, very explosive at times and reactive to a situation.

I know I'm straying a lot, but like I said, there's years—you're going on.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): I'll pass it on to Ms. DiNovo.

Ms. Cheri DiNovo: Thank you so much for coming and presenting and sharing your expertise.

We've heard from other presenters about FASD—the lack of diagnostic ability of the communities to even get a diagnosis and the fact that it's not covered by OHIP. Those are two obvious things.

You mentioned that you'd like to see programs in place. Can you think of a program that would make a difference? Is there one you can think of that we should be doing right away for FASD kids?

Ms. Marilyn Leiterman: Absolutely. Number one: Listening to the parent on the needs of the child would be your priority. Anti-bullying programs that are starting within the schools are good. Mentoring is more important than anything. If these children have one person who believes in them, who's standing in their corner to help them, it will make a difference for them the rest of their lives. Many of these children are set aside. They're on the fringe. They're misunderstood. They're looked at as odd or weird or different, so they lose any strength they had and they start failing, and then they go to violence, drugs, crime etc. very often.

There are some good cases. For instance, with my youngest, we're hyper-vigilant with everything that we do with this child. But a lot of children will never be

diagnosed. The diagnosis piece is important, but we know that not everyone is going to be diagnosed and they're still going to suffer with this disability for the rest of their lives.

So listen to the parent; listen to the needs of the parent to help the child for the programs.

But I would say, number one, that mentoring would be huge—and looking at the child's ability level and working with them at that ability. I have horror stories of kids coming home and having homework to do, and they're just done. By the time school is over, they're done; they can't do any more. They're made to do homework for the next day, say, and they're super frustrated. They don't want to go to school anymore; they want to quit. So in my household, I say, "No, we're not doing any homework."

The Chair (Mrs. Laura Albanese): Thank you very much, again, for your input to the committee. You have some valuable suggestions, and it helps us to learn more about FASD.

Ms. Marilyn Leiterman: Thank you very much for having me. As far as programs go, I could sit down and probably write out a very long list.

The Chair (Mrs. Laura Albanese): You may want to submit that to the committee.

Ms. Marilyn Leiterman: Sure.

The Chair (Mrs. Laura Albanese): Thank you.

SIoux LOOKOUT FIRST NATIONS HEALTH AUTHORITY

The Chair (Mrs. Laura Albanese): We'll now be joined by the Sioux Lookout First Nations Health Authority via teleconference.

Ms. Janet Gordon: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon. How are you?

Ms. Janet Gordon: We're good. My name is Janet Gordon. I'm a director of health services for the organization. With me are Susan Chapman, a health services supervisor, and Christine Sawanas, who works in the MMW—Mashkikiwininiwag Mazinaatesijigan Wichiiwewin—program, which is a program that we are in partnership with Surrey Place to coordinate and provide clinical services for clients in our community.

Can I go ahead?

The Chair (Mrs. Laura Albanese): Yes, you can go ahead.

Ms. Janet Gordon: Okay. We would like to thank you for giving us an opportunity to make a presentation to you about our area, about our organization and about the programs that we deliver for the developmental services.

Sioux Lookout First Nations Health Authority is a regional organization for the communities that are north of Sioux Lookout. We work with 31 First Nations communities. We have approximately 25,000 people that we provide services to—not just in developmental services, but in other health care services that we provide.

Most of these communities are remote, fly-in communities. There are a few communities that are accessible by road, but we provide a varied number of services. We have manage physician services for a community. We have programs like the tuberculosis control program, and we also have mental health and counselling that we provide.

1340

We have other programs, like the community wellness response program, which deals mainly with addiction services. We have a needle exchange program. Then we also have the developmental services program, which is what we're going to talk about, in the areas of transition and clinical support.

We also have hostel services that we oversee and have, so we have accommodations of up to 100 beds for people that need to have additional medical care or tests and that need to come out to Sioux Lookout.

We have a board of directors who are from our communities. We also have a chiefs committee on Health that provides us with support and direction. We work with other health care organizations, such as the hospital Meno Ya Win Health Centre. We work together on new initiatives, or we also keep each other informed with the health services that we provide.

So our program—the MMW program—is such that our money flows through Surrey Place. This program gives us an opportunity to provide clinical and psychological services in terms of assessment and counselling to our clients within the 31 First Nation communities.

We also have the transition program, which is in partnership with Community Living in Sioux Lookout. This transition program is for ages 16 to 24. The program is to increase and strengthen clients' involvement with the community, whether it's in a work environment or a schooling environment, just to support them that way.

We've been doing these programs for about seven years, and plus the transition program came into that and we were able to have that program longer. We've had 109 referrals to date. Now, it could be more in the earlier years. At this point, we have 55 active files between our two programs, and we have two workers who we have within these two programs.

So our community infrastructure, as we talked about, is remote. The way that we deliver care is through Telehealth, and we also have an outreach program where we go into the community.

As you know, most of our communities have poor infrastructure, in terms of recreational activities. We have a poor economic base in our communities, so there is a high unemployment rate in our communities, and people rely on the welfare system. Because of remoteness, we also have a high cost of living in terms of food, clothing, hydro, all those things, so it really affects our clientele.

In terms of infrastructure, we have overcrowded housing and poor housing conditions and problems with adequate access if our clients have physical disabilities as well as developmental disabilities that they might have.

A lot of our issues are that we have individuals who tend to not be identified early with developmental

disabilities, just because there are not enough services on the ground to be able to provide that expert assessment and follow-up. We have a lack of specialized community services for all of our communities. They could also be misdiagnosed.

The school programs don't have adequate programming that would better support people with developmental disabilities. Most of our communities also have limited school access. Some of our communities only go up to grade 8. There might be some that go up to grade 10. Very few go up to grade 12, so if people have to go to school past that, they have to leave their home to do that.

Those are some of our issues. Certainly, the high cost of food also leads to poor nutrition, and we also have no means of providing respite services to families that have family members who have developmental disabilities. Just on that—and with our communities, I don't know if you're aware of this, for the last 15 years, I believe, we've had a high number of suicides in our communities. I think we probably pretty much have—maybe 300 suicides and a huge number of suicide attempts.

In the last five years, we've had huge issues with addiction, mainly around a huge increase in OxyContin addiction issues in all of our communities. With these areas, it really has impacted on people who are marginalized already in our communities in many ways. So when they are in a family that has these issues, then they're pretty much further compromised in terms of their well-being and safety.

The other issue that we also have is certainly FASD; it's a significant issue in all of our communities. Certainly, poor diagnoses or late diagnoses—and it's due to a lack of resources that are available to our communities, whether it's expertise or whether it's on the ground to support these communities further.

I guess there is a systematic issue of not having enough resources for our program on the ground, and that we're trying to provide services to 31 communities with two people, supported by a team from Toronto, and that we are stretched to deliver service and at least trying to monitor the clientele that we have.

1350

Certainly, one of the other issues that we also have looked at that we have issues with is around training for our staff, as well, that's limited in this area.

That's a really quick overview of our program and some of the challenges that we have and the gaps that we see in our communities.

The other thing that I should mention is that one of the huge issues also is language. What happens in our communities is sometimes when people are born with developmental delays—a lot of times they end up with their grandparents, and their grandparents only speak their language, so certainly there are issues around language barriers in terms of providing support to that family. A lot of times, when people end up, say, in the justice system, if they are removed from their communities and then end up in jail, it's something with no support, and it certainly creates a lot of other issues in terms of removing them from their home and things like that.

Navigating other systems like health care, mental health services and developmental services is, I think, even more challenging for these people who are our clients, to navigate the system, and sometimes their families are not able to support them in that area as well.

Certainly, I think we don't have anybody on the ground who could support these families. We do it by visiting them at home or talking to them on the telephone or doing it through Telehealth, but nobody to provide them with ongoing support if they need it right at the community level.

The Chair (Mrs. Laura Albanese): Thank you, first of all, for illustrating so well the services that you do offer and the challenges that are faced by the community that you serve. We have about a minute each. Ms. Jones.

Ms. Sylvia Jones: Very quickly, I wonder if you could share with the committee where the diagnosis takes place. We've heard a lot about FASD, but whenever you are trying to assist families and children, where is the diagnosis happening?

Ms. Janet Gordon: In terms of FASD, the diagnosis happens for our current clients through Surrey Place. I guess FASD could be one of those diagnoses, right?

Ms. Sylvia Jones: Yes.

Ms. Janet Gordon: We used to have an FASD program, which is not in existence any more. I know some of our physicians have gone ahead and have gotten extra training around FASD, so they might diagnose and do a referral based on their knowledge. Then we have a local support which is called Firefly, which could also do some diagnosis up here.

Part of the problem around developmental delay for the support or service that we're trying to do is non-insured health benefits which are funded through Health Canada will not fund for people to get assessed or people to get treatment around that area. So that's a huge barrier, whether it's from birth or whether people are needing help right now as they get older.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Just a quick question, and thank you so much for your presentation. What one thing could we do to make your job easier? Is there one thing that this committee could recommend, if you could put that forward?

Ms. Janet Gordon: I think one recommendation, I guess, would be that we would have a more robust system for supporting people, whether it's at the community level or whether it's at the referral level here in terms of treatment or whether they need to be in a group home situation.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: That was going to be my question.

I would like to ask, if you could put your recommendations in writing to the committee, regardless of which level of government is responsible, and put that forward to us, because I think that there are many issues here that need to be unpacked and that should be addressed.

Ms. Janet Gordon: Yes. We could do that certainly. We'd be happy to do that. When would you expect that by, just so that we—

Ms. Mitzie Hunter: In the next couple of weeks. The committee will continue to do its work over the course of the next few weeks.

Ms. Janet Gordon: Okay.

The Chair (Mrs. Laura Albanese): Within the next couple of weeks would be great.

Ms. Janet Gordon: Okay. I mean, we have most of it in writing, so I don't think there's much to it, I think; reformat it and make our recommendations really stand out for our communities. That'll be good.

The Chair (Mrs. Laura Albanese): That's fine, and thank you again for presenting this afternoon.

MS. DIANA BRAMMALL

The Chair (Mrs. Laura Albanese): We now welcome Diana Brammall. I hope that pronunciation is right.

Ms. Diana Brammall: Yes, it is.

The Chair (Mrs. Laura Albanese): Good afternoon and welcome to our committee.

Ms. Diana Brammall: Good afternoon.

The Chair (Mrs. Laura Albanese): Where are you calling from?

Ms. Diana Brammall: I am calling from the big village of Highgate, Ontario. I am about 45 minutes west of London.

The Chair (Mrs. Laura Albanese): Okay. Welcome again. You will have 20 minutes for your presentation. Should it be shorter, that would allow for questions from the committee. You may begin at any time.

Ms. Diana Brammall: Good afternoon. My name is Diana Brammall, and I am a parent, sister, community member and advocate. I would first like to thank this committee for undertaking this important review of supports and services for the disabled population. I will not be going through my original submission page by page due to time constraints, and will focus on the systemic issues that have caught my attention during the past 16 years of accessing supports and services for my brother who has Down syndrome.

My brother also has anxiety disorder and is deemed non-verbal due to unintelligible speech. He wears bilateral hearing aids and uses a Telus smart electronic speech output device to communicate outside of his immediate circle of family and friends. My brother will turn 20 this summer and has been in my care since he was 39 months old. He was transferred to my care from family services in Nova Scotia to Peel region in Ontario.

Our first meeting with our family's physician set the course for the next 10 years of my brother's life and was instrumental in the huge gains he made during those first 10 years in my care. Family health teams were not yet developed but my family physician worked in a multi-physician office and was one of the first to become a family health team, once they were implemented.

The first question the doctor asked me was if we wanted the team approach or the community approach. The team approach would mean a referral to SickKids in Toronto, and they would assign all specialists, or we could choose our own specialists in the community and be referred to Erinoak. We chose the community approach as I already had two children who had accessed varied community pediatric specialists and I was comfortable with our quality of care.

All individuals receive their diagnosis from a member of the medical community. I would stress that the starting point for data collection is with the medical community. A central reporting body for doctors and clinicians to report a new DD diagnosis would ensure that all individuals are represented in the data. Conditions that are not present at birth but are diagnosed at later stages of development, such as fragile X or autism, could then be captured in the data collection process, giving a truer picture of the numbers of individuals requiring services.

1400

Another critical area is communication between patient and doctor, especially for those with verbal communication disorders. The use of PIC symbols in the medical community is a wonderful tool that is fully implemented and utilized in the United Kingdom.

My brother was fully integrated through elementary school, and his therapy supports were coordinated by CCACs through the various therapists at Erinoak. This is not the same standard across the province. In Chatham-Kent, the therapists are coordinated and employed by CCACs. The regional children's treatment centres and Bloorview offer services to our population that cannot be matched in terms of expertise.

Erinoak was a lifeline for our family and offered access to one of the most important aspects of supporting a child or adult with a developmental disability, and that was a behaviour therapist or behaviour supports. Two of the most important people in my brother's life, in terms of our family understanding him, were the behaviour therapist and the developmental pediatrician that were available to us the entire 10 years we lived in the region of Peel. Since moving to Chatham-Kent, those two very important pieces of our puzzle are missing.

Satellite programs are already utilized in many medical facilities and would fill an immediate void for these services in our area. Investing in expanding the services offered at the treatment centres and removing the age restraints for funding would open up a wealth of talent, ideas and resources from a diverse group of expertise and specialties. An expansion of these services would also serve the non-verbal population that is virtually eliminated from services once they turn 18, if you reside outside of the GTA.

As a member of the special education advisory committee for the Lambton Kent District School Board, I was extremely dismayed to see the interpretation of policy directives by board administration. Although legislation and policies are specifically put in place for equal access, the move between school boards was an eye-opener for me as an advocate.

To say the school boards have absolute control over their individual jurisdictions is putting it mildly. In spite of all the issues that my brother experienced within the Lambton Kent District School Board, to this day I have not had a personal conversation with the man at the top. The superintendents and directors act like a bunch of ruling-class kings who don't need to concern themselves with the peasants. This is a direct contrast to the relationships with the board personnel at the Peel district public school board.

The systemic issue within the school system is not due to a lack of policies or legislation. It can be directly attributed to the beliefs and attitudes of the school board leaders. Access to services should not be dependent on the beliefs of a small group of leaders.

My written submission goes into greater detail of the systemic issues my brother faced, once relocated to the Lambton Kent District School Board, and they include access to services that you have already heard are fully funded by the Ministry of Education, such as hearing equipment and communication aids.

In our 10 years with the Peel board, I only had to advocate on my brother's behalf twice, when new principals came into the school. Since moving into the Lambton Kent District School Board, I have had to use my skills as a union president to get services, and it has been a continuous, ongoing process that won't end until he graduates next year.

Although I haven't made contact yet, I will, in the next six months, be connecting with St. Clair College in Chatham. They currently have a program called Options, which is targeted towards those with developmental disabilities. Unfortunately, this program is only available to approximately 15% of the disabled population that it is intended to serve, as the prerequisites to qualify for the program eliminate any individual who requires support to travel to and from the college.

My brother has expressed an interest to go to college. My other children have gone to college, so my brother sees this as a normal part of life and growing up. He will apply to St. Clair College, and although he does not have enough Passport funding to cover his entire support needs to attend as a part-time student, we will, as a family, ensure that he is still able to access the opportunity. I don't expect this to be an easy request, but we'll rely on the Ontario Human Rights Code to argue his right to attend, if it's necessary.

I have been following the Law Society's review of our consent and capacity legislation with great interest. I am in a different position than most of your presenters who are parents, as I am a sister, and the federal laws for the RDSP did not mention siblings in their definition. I opened my brother's RDSP the year after they were first offered and have enjoyed watching the balance grow quickly with the federal bond and grants that are applied, along with our own contributions.

Once my brother turned 18, though, in 2012, the law automatically determined he was an adult and the bank sent a letter requesting to make him the plan holder. This

is not possible, as he is not contractually competent. Because the federal legislation did not specifically name siblings, I would require legal guardianship to continue as the plan holder. As a former union president, I have an issue with taking someone's rights from them and was frustrated with trying to explain to the bank that I could not, in good conscience, take away his rights in order to protect them.

I then contacted a lawyer who specializes in disability law and was advised to just wait it out, as the legislation I was seeking was going to be forthcoming in the new year. I did receive a letter this past October from the bank, informing us that a letter from our doctor explaining that my brother was not capable of managing his own finances would be sufficient to have me continue as plan holder.

I will be purchasing a house in Chatham for my brother so he has the option of living in the city or in the country as he matures. I am hoping the new consent and capacity legislation will help in the process of arranging his life with the same legal protections that are afforded to the rest of society without removing those very rights I am trying to protect.

I mention the house purchase because if you review the legal process of purchasing a home, how does one, without the legal capacity for consent, sign for a mortgage? How do they build a credit rating? These are the types of issues that I will be facing in my attempt to set up his life and not impact my own financial situation negatively.

PLAN Canada is an effective resource for families but is not available across the province. PLAN is affiliated with professionals who deal specifically with our population. This is a very important piece of the puzzle that is missing for many families: the ability and knowledge required to plan for a person's entire life, covering all aspects of financials, taxation, will and estates, RDSPs etc. You need a different expertise than what is available generically. PLAN brings those professionals together and offers the resources to parents in easy-to-understand workshops that are accessible online and in person.

The first page of my submission is entitled *Developmental Services: Two Regions, Two Realities—the Numbers*. As a chief negotiator against a large multinational corporation, my research usually includes a review of financials. When I reviewed the CRA website for charities and funding provided to the three Community Living organizations I've had experience with in the past 16 years, I was absolutely dumbfounded. The discrepancy between the two jurisdictions is blatant and unacceptable. We cannot, as a society, continue to throw money at agencies and institutions that show absolutely no regard for the public purse.

I contacted Community Living Chatham-Kent on numerous occasions to get further clarification on their posted numbers, but was given the runaround by the executive director and HR manager.

Brampton Caledon Community Living has their information readily available and provided answers to my

inquiries immediately. Again, if I look to legislation and policies of the ministries and the agencies themselves, I can see that the language is there to correct this blatant misuse of public funds, but what I can't find is someone who is willing to do anything about it.

On page 21 of my submission, you will find a list of all the individuals who I sent a copy of my submission to. From that list, I have only heard from the St. Clair Catholic school board, the MCSS and this committee.

The St. Clair school board was concerned about the lack of coordination in our municipality, and they do their best within the confines of those powers. They are more successful at this than the public board.

The MCSS thought I had sent the submission to them by mistake. When I elaborated that the issues contained within were largely within the jurisdiction of their office, I was given a thank-you and have not heard anything since.

Families are grateful that the institutions are closed. I had a family member who was in Huronia when we were children. She was a few years older than me. The conditions we would find her in when we visited made a lasting impression on me that I never want to see repeated for this population again.

For most parents and caregivers, we don't care for our children with the thought of, "I can't wait for them to move into a group home." For most parents and caregivers, this comes at a point of crisis. That is a very important point that I cannot emphasize enough. Group homes and long-term-care facilities are not where we dream for our loved ones to be. It's where they end up because that's all that is offered as a solution to our long-term issues of, "What happens to them when I am gone?"

I have had a very difficult time attempting to understand the process for accessing services through DSO. When we apply, we are assigned to box headings such as community participation supports, residential supports or person-directed planning etc. Each of these box headings also has subcategories, such as "Passport" under community participation supports, and "group living" under residential supports.

1410

I have been unable to get a straight answer to my question from any agency or ministry and was only told by the MCSS that if we were not interested in group living residential supports, then our name should not be on that list. I had to argue with our DSO representative to have my brother's name removed from the group living subheading check box. I'm the only individual in my extended group of disabled caregivers who has removed their loved one's name from the list. I point this out because when the government released the \$42.5 million, my brother's Passport amount was increased significantly. It more than doubled. I was excited and immediately started contacting the other disabled caregivers and was surprised and perplexed that none of my peers, many who are near crisis themselves, were not included in the same financial windfall that my brother received.

There needs to be more and better communication from the MCSS about the changes that are taking place.

Our area has not had a presentation to explain any of the workings of this new system since late 2011, early 2012. Why was my brother's Passport increased and not others in my community with a greater need? Why is the priority access system in our area offering day program spots to students who are still eligible for two to three years of more schooling through the Ministry of Education, while students who have recently graduated sit at home and do nothing? Is this considered a collaborative effort under the MCSS? These are questions that I have been unable to get answers to.

I have read the Hansard transcripts for all the select committee meetings that have already taken place, and I would like to speak to the union side of this issue. I would like to reiterate that families don't seek group home living. It is the only option that most know is available. I would also like to point out that there are other ways to maintain a unionized skilled workforce without having a physical work location to be organized out of. Standards of care are increased when we have well-paid, full-time educated staff. A union helps ensure that those standards are maintained.

Many caregivers are here with me in spirit today from my community of Chatham-Kent. We thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We do have about two minutes for each party to comment or ask questions. It would be Ms. DiNovo who would start this round.

Ms. Cheri DiNovo: Thank you, Diana, very much for your presentation. I have a question related to the point you were just making in the last moment there. When I was in Sweden, there was a program there where unionized—this was a care-at-home program, assistance for families who wanted to maintain their offspring or their brother, who have a family member with developmental disabilities, but they were unionized and they were supervised. But they were homeworkers. Is that what you are pointing to, that kind of system?

Ms. Diana Brammall: That is the exact kind of system that I'm referring to. I have made contact with Unifor to discuss starting a community chapter for just such a thing.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Any further questions? Ms. Wong?

Ms. Soo Wong: Thank you very much, Madam Chair. Diana, I'm particularly interested to hear more about your frustrations dealing with the Lambton Kent school board, because you went from the Peel District School Board with a pretty good support network for your brother, yet when you moved from one jurisdiction to another, I sense from your comments to our committee that you had lots of challenges. Can you elaborate further with respect to the director and the superintendent, with respect to your advocacy work, but also to ensure that your brother receives the proper resource supports so that he will be successful?

Ms. Diana Brammall: Those took many years to develop. It took me almost four years. It wasn't until last

year, which was his fourth year in the Lambton Kent district school system, where I could actually say he had a successful year and he progressed. It was the first year that he didn't stay the same or regress, and a large part of that was those supports that he lost once he moved into their system. There was no behaviour support. The staff were not trained, or if they were trained, they weren't utilizing that training to deal with these students appropriately.

With the non-verbal population, or those that are deemed non-verbal—my brother speaks; my brother talks. We have conversations. Other people don't understand those conversations, though. So he's at an advantage to true non-verbal people because he is able to communicate somewhat. If it wasn't for that ability to communicate, it may have taken me much longer to figure out where his supports were lacking.

Ms. Soo Wong: Thank you for sharing your story with us.

Ms. Diana Brammall: You're welcome.

The Chair (Mrs. Laura Albanese): Diana, thank you again—oh, we have Mrs. Elliott who would like to say something.

Mrs. Christine Elliott: Thank you very much again, Diana, for your presentation. I was just interested in asking a little bit more about the Passport funding that your brother just received an increase in. I've heard from other families that all of a sudden it has just sort of appeared with no particular explanation. Is that what happened in your case?

Ms. Diana Brammall: Very much so. It consisted of a phone call to say I was receiving more funding, and then I received a letter with the new funding amount and a package explaining the new rules for spending those amounts.

Mrs. Christine Elliott: Okay. Thank you very much.

Ms. Diana Brammall: You're welcome.

The Chair (Mrs. Laura Albanese): Thank you.

DUNDAS LIVING CENTRE

The Chair (Mrs. Laura Albanese): We'll now move on to Martha Fox, board member with the Dundas Living Centre. Hello?

Ms. Martha Fox: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon.

Ms. Martha Fox: Good afternoon.

The Chair (Mrs. Laura Albanese): Welcome to our committee. We're ready for your presentation. You will have up to 20 minutes to speak to us. Should the time be less than that, then there will be an opportunity for questions and comments on behalf of the members of the committee. You may start at any time.

Ms. Martha Fox: Thank you very much. Also in attendance with me is Dr. Janice Tomlinson, who is also a member of the board of the Dundas Living Centre.

Dr. Janice Tomlinson: Hello. Good afternoon.

Ms. Martha Fox: The board, our families and our community partners welcome this opportunity to provide

our thoughts and experiences for consideration by members of the select committee. Thank you very much.

Our board is a non-profit charitable organization which represents individuals with developmental and additional disabilities who reside in Dundas, Hamilton, Flamborough, Jerseyville, Ancaster and Stoney Creek. We also represent their families and numerous community partners who have been integral to the development of these individuals as citizens and contributing members of their communities.

For the past eight years, our board, parents, caregiver volunteers and community partners have been working toward one goal; that is, to create an intentional community where individuals with developmental disabilities may transition from their family homes to a residential home in their community where they may continue to attend their day programs, continue to work, participate in volunteer activities and live full and active lives in an environment that is safe and secure and which fosters independence and individual choice.

Parents and families of adult children with disabilities in the Hamilton region, and I would suggest in the entire province, have a common bond: critical planning for the future of their adult children when they, the parents, can no longer care for them. These families know and have been meeting the unique needs and desires of their sons and daughters as a lifetime priority. They are in the best position to design and establish a residential home that will build on current long-term friendships and peer supports within this adult group while utilizing family, volunteer and community supports and paid staff.

These adults currently live with their parents who are in their senior years, parents who are increasingly less physically and emotionally able to care for them. Fifty per cent of these caregivers are on their own. Many have lost members of their extended family who were also providing some care relief or who were part of a future care plan. There is continual stress as parents worry about securing long-term care for their adult children. The need is great and immediate.

The model that we envision will provide a superb community home and be remarkably productive, mutually beneficial and sustainable well under market costs. It takes advantage of currently underutilized vacant space in our community and is based on significant sustainable partnerships with others who are elderly and/or low-income. Being innovative and cost-effective, accessing underutilized space and partnering with marginalized groups in our community are elements which have been dictated to us by the Ministry of Community and Social Services over the past eight years.

1420

Despite adhering to direction from Madame Meilleur, former Minister of Community and Social Services, and more recently initial encouragement and advice from the current minister, Ted McMeekin, our proposal for a residential home as a pilot project, easily replicable in other communities in the province, has been dismissed.

Minister McMeekin has indicated that our model cannot happen and that his ministry has no legal authority

to support our proposal, that doing so would be unfair to those with greater needs. He has stated that fairness demands that places in residential settings be allocated to those with the greatest need and that a standardized assessment process administered in a consistent manner supports the determination of need." He has also stated that though there is a need to seek creative partnerships, any proposal seeking public funds must adhere to the basic principles and legislative requirements of the developmental services system.

I want to offer that all of our sons and daughters have been assessed through a Developmental Services Ontario office and many have been waiting for residential supports consideration for 20 years.

Surely Minister McMeekin realizes that the system is flawed and that no amount of policy creation and money is going to address current housing needs of those with disabilities unless new and innovative solutions are in place to stop the growing numbers of those in crisis in the first place.

Much of our current dilemma is that good public policy and effective service funding of the past has been replaced by huge bureaucracies that force families to fit into existing and inflexible systems and that penalize or dismiss families that are trying to initiate thoughtful and long-term solutions for long-term, sustainable options for residential planning and supports. For a truly equitable system, some individuals may need to be treated differently. An example would be to have a parallel funding route apart from response to crisis which would support families working together with their adult children to create cost-effective residential options that are both economical and reflective of the lifelong care required of their sons and daughters.

Right now these families are forced to engage in planning only when critical situations arise and choice is limited and often imposed. The Dundas Living Centre's philosophy is founded on the UN Convention on the Rights of Persons with Disabilities, ratified by Canada on March 11, 2010, which states that persons with disabilities have equal rights to choose their place of residence, where and with whom they live on an equal basis with others, and that they have residential and other community support services to maximize inclusion and participation in their community.

Our sons and daughters have spoken. They have chosen their place of residence and with whom they wish to live, just as our neurotypical sons and daughters have had the option of doing. We cannot deprive them of this right.

The model of the Dundas Living Centre provides the government of Ontario with one long-term option in assisting people with developmental disabilities, an option that moves 20 people off the Developmental Services Ontario list, that provides safe and affordable housing and, most importantly, is the choice of the adults with developmental disabilities, their parents and caregivers. Our current system of providing residential supports is based on a response to crisis and urgency.

Our families have been told support for residential planning for their sons and daughters will not be in place unless the parents are dead or otherwise unable to care for them. We have to start somewhere to develop a parallel and sustainable system of preplanning and pre-emptive solutions to the current crisis-driven system. Our families are trying to circumvent a crisis by finding safe and supportive housing for our adult sons and daughters now, when they can continue to contribute fully in their communities. This group of individuals knows each other, supports each other and are amazing adults, but they need help from the government of Ontario. They cannot live on their own.

In 1983, Community Living Toronto proposed a residential model similar to the Dundas Living Centre model. The government would not fund the model, opting instead for a dispersed model of homes with three to six residents. Now we are faced with waiting lists of numbers reaching 20,000 individuals who require residential housing.

"Ontario must move beyond the crisis-driven system that has essentially produced the housing crisis now confronting adults with developmental disabilities and their families." That quote is from *Ending the Wait: An Action Agenda to Address the Housing Crisis Confronting Ontario Adults with Developmental Disabilities*, from the Ministry of Community and Social Services, September 2013.

Chris Beasley, chief executive officer of Community Living Ontario, wrote in a letter to me last October, "When I first got into this field 15 years ago, I thought that group homes were the only option for our kids. I now realize that there are a range of other possibilities. Unfortunately, scarce dollars and long waiting lists make these options difficult to realize."

We are suggesting that other models, such as the Dundas Living Centre, should be considered by the government and could be considered as pilot projects, with a research base to find out the strengths and needs of the model and to determine criteria for ensuring success. This option has the potential to significantly reduce the waiting lists referenced by Mr. Beasley and at more than 40% less cost per year than the traditional option of group home residence.

The Ministry of Community and Social Services needs help to make decisions that support ideas which are creative, passionate, make common sense and economic sense, and are in the best interests of our most vulnerable citizens.

Premier Kathleen Wynne stated in April of this year, "Families are very innovative, and if we can find a way to put resources in families' hands and have families working together with professionals, we can provide the right programming."

In March of last year, Minister McMeekin said, "The government has obligations to find new and creative entrepreneurial ways to house the developmentally disabled, either individually or in clusters. Maybe regulations or laws need to be changed."

We hope that both the recommendations of this select committee and the expected Ombudsman's report move the province in the right direction and do so quickly. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your presentation.

We have about three minutes for each party to respond. To the government side.

Ms. Mitzie Hunter: Thank you so much for your presentation and for the work that you and these families are doing to get to the goal that you've stated, which is to provide a safe living environment for your children.

I'm wondering about the model that you've described—if there are other partners that you're working with in addition to the families who have come together.

Ms. Martha Fox: Yes, we have been working with—initially it was Contact Hamilton. We have a strong letter of support from them. We've also been working with Rotary. We've been working with Civitan. We have a partnership with the Sisters of St. Joseph. We've also been working with additional contacts with the city of Hamilton. That's some, just off the top of my head.

There is really no level of government or service group in our area that we have not touched base with and worked with over the last eight years. We have quite a number of letters of support from a broad range saying that this option makes sense, is doable right now, and fully supporting where we're headed.

The Chair (Mrs. Laura Albanese): Any further questions? Mrs. Elliott.

Mrs. Christine Elliott: Hello, Martha. It's Christine Elliott. How are you?

Ms. Martha Fox: I'm well. Thanks, Christine. Happy new year.

Mrs. Christine Elliott: Thank you, and to you as well.

Thank you very much for your persistence and the persistence of your group in moving forward with this project. It is truly an innovative solution to a very, very pressing need, and we've been hearing about that constantly in our hearings so far.

1430

As we've discussed in the past, it seems to be that the ministry's concern about this is, first, it might be considered queue-jumping, but in fact, many of your sons and daughters have already been waiting for about 20 years for a placement.

Secondarily, there seems to be a concern about the size of the project, that it's considered too big, that it's considered to be an institution, and that the ministry is sort of dismissing it out of hand.

Could you comment a little bit more on that for the benefit of the committee, please?

Ms. Martha Fox: Certainly. In long discussions with the current minister, Ted McMeekin, who's also our MPP and has known quite a number of the sons and daughters we're talking about since they were young—there has been reference to a waiting list. Most recently, we've been told there isn't a waiting list. It's actually a pool, and individuals in the pool rise to the top of the pool when they are in crisis or in some type of urgent

circumstance. Then they receive whatever level of support that might be, whatever the residential option may be that makes sense at the time.

Of course, what we've also been told is that there's no guarantee that any residential option that comes out of a response to urgency or crisis is going to be in the community where these individuals have grown up and have jobs and volunteer placements and work and day programs etc.

Again, I guess our issue is that the whole idea of a queue is problematic. To indicate that the only way you get residential support and service is if you come to the end of the queue, or you rise to the top of the queue, with the results then being wholly unsatisfactory—in other words, we've been told before that if something happened to George and I, our son Matthew, who's almost 33 and has been waiting for residential support and planning since he was 18—we've been told we'd have to die for him to get support, and that support could be anywhere. So despite the fact that he is fully engaged in work, a job placement, day programming—and I can go on and on—in his community, he could end up in Barrie, with no connections to his community.

So when we talk about a queue, it's a queue you don't want to be in, because the results of coming to the top of the queue are not good. When Minister McMeekin has talked about jumping the queue, what he's really talking about is that we are trying to step off the crisis/urgent-driven response route and offer an option of preplanning and pre-emptive crisis response. That's what is really being discussed.

What has become very clear to us over the many years we've been working on this is that there is absolutely no landscape—and in some circumstances, no understanding—of why parents want to support getting off the urgent-crisis response route and have the option, perhaps through individualized funding or other kinds of mechanisms, through maybe not only the Ministry of Community and Social Services but maybe in consideration with the Ministry of Health etc., to be able to do this pre-emptive planning that doesn't support only a crisis response.

Mrs. Christine Elliott: So you're trying to head off a crisis, and you're trying to be innovative in your solution in a cost-effective way.

Ms. Martha Fox: Absolutely.

Mrs. Christine Elliott: It seems like a winning solution to me, and I certainly would hope that government would take it on, at least as a pilot project.

Ms. Martha Fox: Well, you know, our son requires significant support. We were told that for him to go into a group home tomorrow, it would be \$175,000 a year. With the model that we have, Matthew would be able to move into the Dundas Living Centre, and we'd be looking at an average cost of \$68,000 a year per resident. That is a huge, huge savings for the province.

The Chair (Mrs. Laura Albanese): Thank you. I believe someone—is it Miss Taylor who wants to comment?

Miss Monique Taylor: Yes. Hi, Martha. Thank you so much for joining us today and for bringing your story

to the table. It's something that, as we've been going through the process—I'm from Hamilton Mountain. I've been watching your case and wondering what the issue was and why it wasn't moving forward. I really do appreciate you coming forward and stating that, really, there is no reason other than your families are not in crisis.

Ms. Martha Fox: That's the bottom line. Minister McMeekin has also most recently categorized us as a private group of privileged parents, as Christine mentioned, who are trying to jump the queue. We couldn't hear anything more offensive, quite frankly.

Miss Monique Taylor: Yes, I can imagine. I think it's quite interesting, and I know the need in our community for these kinds of homes. I know many families who are looking for homes for their now-adult children, and this is just the solution that seems would fit perfectly. We know that we need to look at different solutions for different families, because we're not cookie cutters and we can't all be treated the same, that some things work better for some than they will for others. This sounds like a resource that would work for some families who have the ability to do so. I wish you all the best of luck. I hope that this committee will help move things forward for your process also.

Ms. Martha Fox: Thank you. I just wanted to also—I realized I didn't address the inquiry from Christine about an institution. The reality is when I think about an institution, I think about a place where someone is put and they don't have choice. What we are envisioning is about as far away from an institution as you can possibly get and, quite frankly, if our son was placed in a small home where he didn't know anyone and he had no choice, he lost his job, his day program etc. that would be institutionalizing him, not the model we are considering.

I have a lot more information that I certainly could send that maps out the particular model that we're talking about, but I do want to say to the committee that a great number of parents in our groups were offered institutional placements for their sons and daughters when they were infants. I know we were. Both parents said, "No way, no how; we are going to raise our sons and daughters with the support of our communities." And to now have the suggestion that a model that we are envisioning in any way would be reflective of an institution is an incredible slap in the face. As I've said, it's about as far away from an institution or institutional culture as you can possibly get.

The Chair (Mrs. Laura Albanese): I want to thank you for your presentation and for your input, for presenting to us your plans and this project. We are trying to look at the issues. We're trying to get at the core of the issues in a very non-partisan way and looking at multi-ministerial help, because the reason why this committee has been formed is to find a comprehensive developmental services strategy because of the urgent need that currently exists.

You can send us in writing more about your proposal, and that will be welcome. Thank you, Martha, for your time today.

Ms. Martha Fox: Thank you very much and thank you for the honourable work your committee is doing. If there is anything more that we can do to assist moving your agenda forward, we're most happy to do so.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Martha Fox: Thank you kindly.

The Chair (Mrs. Laura Albanese): We are now going to take a small break. The next presenter has cancelled. We will resume at 3 p.m. sharp.

The committee recessed from 1439 to 1500.

MR. GEOFFREY SHEA

The Chair (Mrs. Laura Albanese): And we are back in session. We will now hear from Geoffrey Shea. Hello?

Mr. Geoffrey Shea: Hello.

The Chair (Mrs. Laura Albanese): Hi. Good afternoon. How are you?

Mr. Geoffrey Shea: Good afternoon. Fine, thanks.

The Chair (Mrs. Laura Albanese): We are here, all ready to listen to your presentation. I don't know if you know: You will have up to 20 minutes to talk to us. If your presentation is any shorter than that, then there will be opportunity for questions and comments from the members of the committee.

Mr. Geoffrey Shea: Okay, great. Thanks very much for agreeing to listen to our story. I'm going to speak about our son, Yoschi, who is 20 years old. He was born with a physical disability, and those limitations led to the creation of a developmental disability.

Yoschi was born with quadriplegic cerebral palsy. He can't use his hands or feet. He can't stand or walk. He can't hold things or point or press buttons. He often experiences a spastic tension throughout the left side of his body. This caused his left hip to become dislocated and painful, which resulted in a surgery. Over time, he developed severe scoliosis, which now makes sitting upright in his wheelchair uncomfortable. Yoschi is also very hard of hearing. He wears hearing aids, but he relies on lip-reading to enhance his comprehension. Because he has very little core trunk support, he has difficulty mustering enough breath to make himself understood when he's speaking, so he talks in a whisper.

As a result of all this, he requires 100% assistance throughout the day and also has to be repositioned several times during the night. Someone has to help him by turning the pages when he's reading a book or clicking the mouse when he uses a computer or selecting the music or TV shows that he wants, in feeding, dressing, shopping, going anywhere, and also, of course, interpreting for him when he needs to converse with a person who's not trained to understand his quiet voice.

In two recent DSO-related assessments, Yoschi was identified as having developmental disabilities, compounding his intense medical and physical support needs. He has missed out on many experiences in life and their related developmental milestones. Since he requires constant care and assistance, he has little sense of independence, privacy, responsibility or autonomy. His

communication barriers have prevented him from making friendships.

These things notwithstanding, Yoschi is bright, cheerful and inquisitive. He's finishing up high school this year, doing a co-op placement, writing articles for a local entertainment magazine. He's working on his second documentary film, about young children who have a fear of thunder. He's interested in languages, particularly etymology and foreign languages. He especially enjoyed native studies and parenting in high school, though he struggled with trigonometry and had to retake the course in order to pass.

Yoschi is now eager to expand his engagement with the world. He's interested in exploring post-secondary education. He's intrigued by the notion of independent living, even though he has so little experience with independence. He hopes to make friends. In general, like many people his age, he's ready to embrace life.

That's the story of where we are now.

The past 20 years have been very challenging but also very rewarding. Yoschi's schools have been very accommodating, providing one-on-one EA support throughout the day. We've been receiving enough financial support so that he can have a few hours each day with an attendant. Of course, his mother and I put in a lot of time, but that's to be expected with raising children, whether it's driving to music lessons or hockey games or helping with homework.

Yoschi turned 18 two years ago now, and with high school coming to an end, we're really starting to experience the long-term ramifications of living with a complex disability, and the prospects are very frightening.

First, though, we received a letter from assistant deputy minister David Zuccato around Yoschi's 18th birthday, saying that he would be automatically transferred to Passport funding. That offer was later rescinded, and we've been on various waiting lists since then and have not been receiving any funding. Once the support provided by the school system is over in June, it seems we will be on our own to plan for the rest of his and, indeed, our lives.

In talks with family support services and DSO and other parents, it seems that our options are bleak. These seem to be the alternatives: If Yoschi continues to live at home with us, and we're resourceful and lucky, we might be able to put together, through various funding supports, enough so that he can have eight hours of attendant care per day, perhaps five days a week. That would be enough support to allow both of his parents to continue to work, but it means that all of our non-working hours will be involved in providing for his care. In this scenario, he will not be able to continue his education, because we live in rural Ontario. His social life and ability to explore the world intellectually will revolve around the interests and abilities of his caregivers. Our capability to contribute to his day-to-day needs will diminish with age and our own physical abilities. His needs will be increasingly demanding throughout our retirement, which will not be very rich, since both of our careers have been impacted

by the demands of the last 20 years. And when we die, he will have to radically and quickly adjust to some sort of long-term-care facility.

The next alternative that we can imagine is that Yoschi moves to a long-term facility sooner. From what we understand, these range from quasi-independent living facilities, where he might be eligible for three or four hours per day of attendant support, to nursing home-like facilities with greater staff availability but no opportunity for developing or exercising independent skills.

In these two scenarios, I think we can image this bright, curious, charming young man spending the majority of the rest of his life parked in front of a TV.

The final scenario that we can imagine for our son is one in which he is provided with attendant support for the entire day, and where he can make life choices based on his interests and abilities. He could then move to a city, where he could continue his education. He could carry on interviewing people so that he can write articles and make documentary films. He could meet people and make friends, perhaps find love, and contribute to society with his many abilities and strengths. This is really the only viable model of support—the one that I just outlined—but it's beyond what almost any family could provide.

If the government is going to continue to insist that the responsibility for providing services to adults with disabilities falls to aging parents, we're inviting a series of tragic and heartbreaking ends, in many cases.

Still, we have to acknowledge that the severity of Yoschi's physical needs, combined with his developmental challenges, places him at the far end of the spectrum for any care or support system. But support for these individuals should not be considered optional, provided when and if resources become available. This has to be considered a minimum level of social responsibility.

We, as a society, can say that someone who has a level of need imposed upon them by a physical and/or developmental disability should not be further harmed or stifled by inadequate care, but should be provided with the resources that will allow them to access the same opportunities that the rest of us take for granted.

I know that government resources are limited and balances must be struck, but any level of support less than the one that we're proposing here is, in effect, a punishing sentence imposed by the government on the most disadvantaged members of our society.

I suspect that your recommendations to the House will be multi-faceted, including structural modifications and possible policy revisions. But please, I'm asking that you not settle for creating a foundation for change or a framework for improvement. People who are in situations as extreme as Yoschi's require substantial support and the commensurate investments. So please also recommend dramatically increased funding levels as well.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Geoffrey, for your presentation. You mentioned that you live in rural Ontario. Where are you calling from?

Mr. Geoffrey Shea: We live in the town of Durham, north of Guelph, south of Owen Sound.

The Chair (Mrs. Laura Albanese): Thank you. We will now move to questions, and we will start with Ms. Jones.

Ms. Sylvia Jones: Thank you, Geoffrey. It sounds like you have made a pretty incredible life for your son Yoschi.

Am I correct in hearing that your Special Services at Home funding was pulled at 18 and now you are waiting for Passport.

1510

Mr. Geoffrey Shea: That's right. As I mentioned, we did receive a letter from the ministry saying that that would not be the case. By the time that letter was rescinded and we were told that we did have to apply, it has taken years of being on waiting lists just to even get the application in.

Ms. Sylvia Jones: A bit of a cruel joke. It's one of the things that we are discovering here, the inter-ministerial challenges. It does beg the question of why Special Services at Home doesn't stay in effect as long as the individuals are being served at home, but I guess we'll leave that to further debate.

Your vision for Yoschi; have you had an opportunity to present that, discuss that, with the DSO?

Mr. Geoffrey Shea: Oh yes. We've had meetings with the DSO, and they have prepared a Passport application for us. As I say, it took a couple of years to get that to happen, but we have recently done that. They've recommended some local resources we might look at. There's a respite care facility not too far from here where we might be able to arrange to drop Yoschi off for weekends. But we're trying to plan for his long-term care and life, a life that, eventually, we will not be involved in. None of the options that have been presented to us look remotely tenable.

Ms. Sylvia Jones: I understand. Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you so much, Mr. Shea, for your presentation. I have to say that I was really impressed with Yoschi's achievements in school. I would probably have flunked out of trigonometry, too, just to let you know.

Mr. Geoffrey Shea: Helping with the homework was not easy.

Ms. Cheri DiNovo: I want to follow up on this Passport letter that you got from the ministry: One minute you get it, one minute you don't. When you, which I'm sure you did, asked them, "What's the situation," what did they respond?

Mr. Geoffrey Shea: We didn't ask them about the situation; we just received this letter out of the blue saying that we were getting funding, so we didn't do anything. It said that partway through the following year, we would be contacted about having to update our file and things like that. Then, six months later, we got another letter that said, please contact DSO and get an assess-

ment, and you have to apply for Passport before you can get it.

Ms. Cheri DiNovo: So there was no explanation as to why? Basically, sleight of hand: "Here it is; no it's not"?

Mr. Geoffrey Shea: I think the follow-up letter said that the initial letter was written in error.

Ms. Cheri DiNovo: Ah. Okay.

We've heard from a number of presenters, of course, at this point. One of them suggested that what's really needed is a system of entitlement rather than a welfare system, where it's discretionary, like health care: If you go into a hospital, you get looked after if you have an OHIP card because you need it. Would you support such a movement in thinking?

Mr. Geoffrey Shea: Yes, I think so. I think that's ultimately what I'm looking for, something that, if we determine that these disadvantaged people in our society have this need and have had this need thrust upon them, we need to step up and say that we as a society can take care of that. It shouldn't be a case of going on to waiting lists that are 20 or more years long or providing services when and if resources become available. I think entitlement is a much better way of considering it than, say, charity.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation, Mr. Shea. With regard to your comments about your interest for your son to go on to post-secondary, can you share with the committee some suggestions? I think you also shared with us that you're from rural Ontario and that you are interested in having your son go on to further education. Can you share with us, in terms of support from the Ministry of Training, Colleges and Universities or Ministry of Community and Social Services, how we can help your son so that he can continue on with his education? Can you provide some insight on that part?

Mr. Geoffrey Shea: We've started to research what sorts of options are available. I work in the Ontario university sector, so one option that I could imagine would be that he would attend a college or a university. His communication issues are so limiting, and his physical needs are so great, that he would require an immense amount of support, far greater than any student at the university that I'm associated with has ever received. So that might be kind of pie-in-the-sky or wishful thinking on our part.

I gather that there are college programs that are set up and tailored to people who have physical and developmental disabilities. I don't know very much about them. I think there are some near where you are today, aren't there? Are you in Sudbury?

Ms. Soo Wong: We're in Thunder Bay.

Mr. Geoffrey Shea: In Thunder Bay. Okay. I thought there was one in Sudbury.

So if there was a school that had tailored or tailorable programs, that would be an option as well. Doing something through correspondence is a possibility, but it's not

a very life-expanding opportunity. It further insulates Yoschi from the world, and the insulation that he has experienced in the first 20 years of his life is what has held him back. I mean, the reason that he had so little sense of autonomy, independence or responsibility is because he has been insulated from so much, so I'm eager to see him participate more in the world.

He's interested in education. Participating in school thus far has been the highlight of his life. He does get to get out. He does have people around him, usually all filtered through his one-on-one EA caregivers. But I think that with the little experience that he's had, the idea of continuing school is the best thing that he could imagine happening, and I tend to agree. I'm a big proponent of the value of education and lifelong learning, so I'd love to see him continue to expand in all aspects, intellectually and socially, in ways that further education can provide.

Ms. Soo Wong: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Thank you again for presenting to our committee today. We really appreciate you sharing your story, and hearing about Yoschi's life. Thank you for your suggestions.

Mr. Geoffrey Shea: Okay, thank you. I look forward to seeing your report.

The Chair (Mrs. Laura Albanese): Thank you. Have a good afternoon. Bye-bye.

Mr. Geoffrey Shea: Thank you. Bye-bye.

MS. LOIS HACIO

The Chair (Mrs. Laura Albanese): We'll now call on Lois Hacio. Yes, take a seat wherever you feel most comfortable.

Ms. Lois Hacio: Okay, thank you.

The Chair (Mrs. Laura Albanese): If you need a glass of water, please go ahead and take one. You may start your presentation at any time. I know you were sitting in the back, observing the hearing, so you've heard, more or less, what the rules are. Feel free to go ahead any time.

Ms. Lois Hacio: Good afternoon, committee members. My name is Lois Hacio. I'm here to speak about the quality of assistance for my adult son, who has a mental disability, notably schizophrenia. As well, I would like to talk about housing for the mentally disabled and services provided.

My son is 33 years old. Just a brief history: He had some health problems at age 15, such as chronic rhinitis and tonsillitis, and there were other environmental stressors. At that time, my son demonstrated some abnormal behaviours and so was hospitalized.

Going back to grade 1, his teacher said that he was ADD. He also had difficulty processing verbal information and also had tics from anxiety. She recommended that he repeat grade 1. This affected my son's self-esteem many years later.

In those days, there were no assessments, and no special education teachers to evaluate or assess children

and give them the one-to-one assistance that he or she requires to be successful in school.

1520

My son had no mental health problems from grades 2 to 7. When my son's health did deteriorate in grade 9, I had to take him out of school, and his high school provided a tutor for one course. When he returned to classes that year, he became catatonic in one of his classes and was sent to the hospital, to a psychiatric unit.

After discharge, I requested a tutor for my son but was told by the guidance counsellor that a tutor was not available and they would not provide one, so I home-schooled him myself to finish his grade 9 and later assisted him with nine more credits from adult education, who were very supportive.

He finished his last credit at the age of 30 and received his grade 12 diploma while in the psychiatric hospital, with the assistance of the social worker, psychometrist and a volunteer. Goal-setting is important for those with disabilities, and it's baby steps to get there.

My son has been institutionalized three times long-term, twice for two years and recently for a three-year period, to finally receive housing in February 2012. At one point, between hospitalizations, my son had an apartment. However, his anti-psychotics were being changed most frequently, so he was never stable.

I worked out of town as a special education teacher at the time, and every Friday evening I would drive three hours to get my son groceries and then return back to work early the next day, on a Saturday.

The case workers at his apartment never recorded if he had picked up groceries on his scheduled day, and workers changed from day to day so I could never find out if he was taken out for groceries. Sometimes he would say that he was not feeling well, which meant that he was having hallucinations or delusions, so he would not leave his apartment.

It is desirable that case workers are present seven days a week in an apartment setting, because if someone with a mental illness needs to talk to someone, a trip to the hospital might be avoided. Also, activities are very important as a part of programming for their clients, ideally seven days a week. Most programs with case workers in an apartment setting are five days a week.

In a psychiatric institution, there is structure, healthy meals and a caring staff trained in mental health. Out in the community, in an apartment setting, there can be a lack of structure or access to healthy meals close at hand, which can cause stress. Community kitchens would be an asset, or delivery of a small meal, such as supper, later in the day. Presently, Meals on Wheels have volunteers deliver a lunch for a fee.

In 2010, my son was desperate to get out of the hospital. I phoned numerous agencies to find housing suitable to meet his needs, because the social worker at the psychiatric hospital said no housing was available such as homes for special care or high supportive housing. There was no suitable housing to meet his needs.

Finally, the social worker at the psychiatric hospital found one place run by the Salvation Army where case

workers ran a program five days a week, and so his name was on the list for one year or longer. He was accepted there after an interview process. We took on the lease, and then I received a call from the psychiatrist's intern, who I didn't know. She wanted to know if I wanted my son's name on a list for high supportive housing. I told her we'd just found a place and that the social worker had earlier told us that there was no high supportive housing.

Later, in a meeting with an assertive community treatment team, otherwise known as ACTT, and my son's psychiatrist, it was recommended that he go into high supportive housing with 24-hour care. The ACTT worker stated that they could not see him as often as needed if he had gone into an apartment—only twice a week for one hour, but every day for med delivery.

My son did not want to go to the high supportive group home because it would be with older adults. He also was sent to a high supportive group home while in the hospital, but he demanded to go back to the psychiatric hospital, as the bathrooms flooded two days in a row and this was stressful for him.

There needs to be a variety of housing available for those with mental disabilities, depending on their needs.

At my son's present address, there are other people living there with a similar illness. Sometimes my son has had anxiety caused from one of the clients in the building, and he has gone to the hospital numerous times on a weekend to talk to someone in mental health. This is more likely to occur when the case workers are not there on a weekend, and he always takes an ambulance. On the other hand, he has made some positive friendships with others in the building.

Since February 2012, I have been assisting my son with housekeeping and laundry, and I also bring groceries or meals to him. I have contacted an intake worker at the community care access centre but was told he wasn't eligible for housekeeping unless he has personal care.

Recently, it was recommended to me to still get an assessment with the CCAC. The case worker at my son's residence had told me a year ago that she would put my son's name on a list with Ontario Works for housekeeping, and it would take a year or so to get the assistance. However, I recently learned that this was not done. When I contacted Ontario Works, I was told that they receive funding for housekeeping for clients, but if the funding was to run out and I was the next one on the list, my son would not receive assistance.

On a positive note, the support of the occupational therapists who have taught my son cooking skills has enabled him to cook on his own. The ACT teams previously had occupational therapists; presently, they do not. At the psychiatric hospital, there are occupational therapists, and it was they who contributed to teaching my son this life skill.

I have thought about the Lights model for supportive housing for those with mental disabilities, and it could work as a good model, provided there was 24-hour support and funding for those who need the support.

Four years ago, I inquired with the LHIN regarding funding for high supportive housing. However, I later learned that the funding would go to a home for addictions, since there was already some high supportive housing for mental health but none for addictions.

My son has never taken drugs, as far as I know, but while he was at the psychiatric hospital he told me that he was offered “funny tobacco” by another patient while on a smoke break outside. The nurse later informed me that a patient had brought marijuana into the hospital grounds.

In terms of caring for a disabled child or adult, if the person is not treated with a medication that helps the person, more demands are placed on the caregivers, to the point of exhaustion.

From October 2012 to August 2013, my son’s psychiatrist raised his antipsychotic injection. My son became more delusional, having more hallucinations during that entire period, and I would have to stay with him from 6 p.m. to 12 p.m. at his apartment because of his anxiety. He would put himself in the hospital after every injection. Then he would be discharged from emergency and he would come to my home, where I would have to care for him for at least a week or longer because of his anxiety and positive symptoms. Eventually, I would have to phone the ACT team to tell them that I was exhausted, that I could not care for him any longer at my home and that he would have to go back to his apartment.

I would send numerous reports of observations to the psychiatrist, and my son would end up getting another injection because of doctor meetings being postponed to a later date.

I have seen that high doses of antipsychotic medication, in my son’s case, cause greater side effects and make a person who already has a disability more disabled, with weight gain, changes in hormones and heavy smoking to compensate for more symptoms.

Eventually, my son had a severe reaction to the injectable antipsychotic. When the medication doesn’t work and causes much suffering for the patient, this further consumes a parent’s life and leaves adults with disabilities even more dependent on their parents, with no respite.

In terms of services provided for those with developmental disabilities, compared to someone with only a mental illness, I see in our community that there may be more options for those who have a developmental disability. For example, my neighbour, who is a nurse, has a son with Down syndrome. He lives with her and he requires 24-hour care; she has to do most things for him. He cannot be at home alone while she is at work.

She told me that her son is in a ministry-funded day program called Passport, where she can use funding to pay a suitable worker of her choice \$12 an hour to take her son out into the community for four to five hours per day. This has been a very successful program, allowing her to work and support her son in her home, and it also does allow for caregiver respite.

As my son is the same age but has a mental illness, he is only taken out into the community once or twice a week by an ACT team worker for one hour.

At his apartment, there are case workers, but some of the scheduled activities are not to his interest, and he does enjoy going out into the community. A day program for my son, such as Passport, would suit his needs; however, it is not available to him.

1530

Also, I tried to get respite at one time through Wesway when my son lived with me, but I was told that respite wasn’t available for parents who had a son or daughter with a mental illness; that they were not funded through the LHIN to offer respite.

Just to sum up, quality of life for those with disabilities goes hand in hand with the medications that they may have to take. Some research in Ontario shows that 50% of those with a developmental disability are taking antipsychotics.

I see in our medical system, with psychiatry, the system is not set up to search for an underlying biological problem, and it seems to be a trial-and-error approach. Thomas Insel, director of the National Institute of Mental Health, stated in December 2013, “Diagnoses of mental disabilities is based on clinical symptoms with no objective laboratory measure. We need to begin by collecting the genetic, imaging, physiologic, and cognitive data to see how all the data—not just the symptoms—cluster and how these clusters relate to treatment response. Patients with mental disorders deserve better.” This would be personalized mental health care and would require an interdisciplinary team.

We need to provide our hospitals with the research, funds and beds to improve the quality of life for those with disabilities and their families.

Thank you.

The Chair (Mrs. Laura Albanese): We thank you for sharing your story.

We have two minutes for each party for questions or comments. Miss Taylor.

Miss Monique Taylor: Good afternoon. Thank you so much for taking the time to come and share your story with us. I was not part of the Legislative Assembly at the time when I know some members of this committee did the exact same thing for mental health issues. I’m sure that they’ll be speaking on that. This is the first time that it has been brought to our attention here, so I’m really happy to hear your piece of that puzzle. You’re right: We’re working on one when we have another one falling behind. It’s so unfortunate. It just seems like it’s a continuous circle, what’s happening here in the province.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you so much for bringing this forward. It is interesting. What you described really should be a developmental disability, if it’s a mental developmental—your son clearly exhibited some issues from an early age. I thank you; you’re the first person who has come forward with the mental illness label that, of course, denies him funding from other pockets—not that there’s much out there; he’d be on a waiting list for another 12 years for it. But it is interesting, and I hadn’t realized that that silo had been created.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: Thank you very much for being here today and sharing your story with us.

We had several experts come before the committee from the Centre for Addiction and Mental Health, and there were some comments made about dual diagnosis and the mental health correlation piece.

On the last page of your presentation, you talked about the inequity between the developmental services currently being provided for those—compared to those with only mental health illnesses versus those with developmental disabilities. Can you share with us, if you were to have one wish in terms of priorities, what would that be—to provide you with the respite, provide you with the support so that you have a quality of life and so does your son?

Ms. Lois Hacio: I like the Lights idea of supportive housing. However, his needs are high, so I would say he would require someone having to be in the building 24/7. Basically, it's like high supportive housing. It's very important that they have activities and learn life skills and set goals—goal-setting. I do really like that Lights idea for having to choose something that would be suitable.

Ms. Soo Wong: Can you follow up with the Clerk to share that model of Lights with us so that we can follow and hear more about it? That would be really helpful if—

Interjection.

Ms. Soo Wong: Oh, we have that. I see from my colleague across from us. Okay.

Then in the last paragraph of your presentation to us, I'm particularly struck about some of the data you share with us today. About 50% of those with developmental disability also have some antipsychotic—

Ms. Lois Hacio: Actually, I heard that from a previous proceeding. One of the other doctors had mentioned that out of 50,000 people that they looked at from ODSP records, 25,000 were on antipsychotics, and not just one—five to 10. And there was no doctor follow-up or it was very difficult for them to see a doctor. I find the same problem because there's a lack of psychiatrists. It's very difficult to see a doctor sometimes.

Ms. Soo Wong: Okay, thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Elliott?

Mrs. Christine Elliott: Thank you very much for joining us today and for making your presentation. I'm so sorry that you've had so many difficulties with your son over the years. I can tell you that there are three members of this committee, myself, Ms. Jones and Mr. Balkissoon, who served on the previous Select Committee on Mental Health and Addictions. Our report came out a few years ago and in many ways this report was sort of a subset of that group because we realized that there were people who were dually diagnosed or who had a developmental disability that also needed services. I would say the need for service is equally great in both the developmental services sector and the mental health sector. We addressed a lot of the issues that you're speaking of today in our report.

The government is in the process of unfolding a mental health strategy. It's been aimed at children and youth so far, but my understanding is they are moving towards addressing some of the issues in the adult sector. We'd be happy to send a copy of the report to you or indicate to you where you can find it. We'd certainly be happy to get your feedback to see if it satisfactorily addresses the issues that you've been speaking about today. But certainly we think that the issues in the mental health world are equally as important and we're committed to doing something about that as well. So thank you.

The Chair (Mrs. Laura Albanese): Ms. Hacio, thank you again for being with us today and sharing your story. It's truly appreciated.

Ms. Lois Hacio: Thanks very much.

MS. PATTI ZIMMERMANN

MS. JAN HUDYMA

The Chair (Mrs. Laura Albanese): Now we call on Patti Zimmermann and Jan Hudyma to come forward. Good afternoon. Thank you for presenting to our committee. You will have up to 20 minutes to speak to us. Should your presentation be any shorter, then there will be opportunity for questions that will be asked by members of the committee. You may begin any time you feel comfortable. I know we're all getting a copy of a handout that you have provided us with.

Ms. Patti Zimmermann: Do I need to use this or can I just talk the way I want to talk?

The Chair (Mrs. Laura Albanese): Start just by stating both—

Ms. Patti Zimmermann: Yes. I'm Patti Zimmermann and this is my friend Jan Hudyma.

We both have special needs children—actually young adults. They're both 20 years of age. My girlfriend and I are here representing our children. Erika is my daughter and Jessica is Jan's daughter.

Both of them have special needs. Both of them are autistic and they also have intellectual disabilities and physical disabilities, so it's not just one component. They both need one on one, and they do usually get that through the school provider that they're going to the schools in now.

Sorry, I'm just a little bit nervous here.

We have dedicated our lives, of course, to our children and we want the best for our children. When there is no programming once they finish school—as of this year, they will both be 21 years of age and there will be no more school for them. So what happens to the children? Where do they go? Do they stay home with mom and dad or do they go to programming?

Every single one of you people here gets up in the morning; you have a sense of purpose. Do our daughters have a sense of purpose? If not, why not? Or how come they don't? That's part of our speech today: There is a need of programming. She needs to get up every day and have a sense of purpose as well.

1540

We have more or less come up with ideas and solutions in regard to the problem, which is lack of programming. With the lack of programming, the only way there is an empty spot or an open spot is if some other participants pass away. That's plain and simple how it is. Unfortunately, there are not enough spots, and people have to wait many, many years in order for these areas to open up.

On that note there, I just want to pass it over to my friend Jan. Jan will talk about the solutions that we both have come up with. It has to be a partnership. It has to be networking. It has to be a collaboration between us and, of course, the government. We're not alone. It takes all of us to look after our children, and it should take all of us to look after the young adults and the adults with special needs as well.

Ms. Jan Hudyma: Hi. Our suggestions are pretty simple. We didn't want to reinvent the wheel.

(1) More programs that are economical for parents, caregivers and the government: Specifically, these services will be for adults, so why not use a portion of their ODSP, the Ontario Disability Support Program pension, to pay for the services? The programs would be subsidized for low income, but most would use their pension to pay for the programs.

(2) Network with existing agencies in Thunder Bay, Lutheran Community Care or Wesway. Expand their programs; don't reinvent the wheel.

(3) The curriculum could be based on the secondary schools' special-needs programming, which we both found to be comprehensive. They cover daily living skills as well as recreational activities which enhanced our daughters' quality of life.

Thank you for the opportunity to address you.

The Chair (Mrs. Laura Albanese): And thank you for coming here this afternoon. We will have about five minutes for each party to ask questions and to make comments. Ms. Hunter, I guess, will start.

Ms. Mitzie Hunter: Thank you both for joining us here today and really sharing a part of your family's story with us. I'm interested in your second recommendation to network with existing agencies. You've cited two examples. Can you describe your experience working with such agencies and how that type of networking would enhance their quality of life?

Ms. Jan Hudyma: Well, Lutheran Community Care is the hub—it seems; I haven't had much to do with them yet. My daughter is on a waiting list. They seem to be the hub for assisted living. They do some respite, and they have some apartments, that kind of thing. They seem like a natural choice because they are already up and running. Any involvement I've had with them, they've been wonderful.

Wesway is a respite centre in Thunder Bay. I would imagine both those organizations, if funding became available, might be interested in expanding their services.

Ms. Patti Zimmermann: So it would be like a partnership between Wesway and the group that we're presenting to now. Like I said, Wesway has group homes

around various areas in town here. They have seniors' homes as well, they have for the younger kids, and they have for the teens-young adults as well.

Ms. Mitzie Hunter: So what are you doing to prepare for when your daughters turn 21?

Ms. Patti Zimmermann: I've been phoning Bill Mauro almost every month and talking to him and mentioning to him that there needs to be programming for the kids. Unfortunately, the lack of money because of all these—wherever the money should be going; as much advocating as I can do, as well as Jan is doing, too, talking to the schools, trying to be in partnerships with the schools. There needs to be more of that. People need to hear of our plight and say, "Oh, okay. Now I see it."

I don't know if any of you people here have special-needs kids; if you do, then you might know what it's like with autistic children. Then when you have other disabilities as well, there's a lot that goes into play: OT/PT, speech, not to mention they can't be left by themselves. I just can't go out for a night with my husband and say, "Okay, Monique, do you want to take my daughter for the night?" It's not going to happen. I need somebody who knows about autism; you know, she has seizures. Jan's daughter has physical disabilities. I mean, it's nice that you people are all here, but you haven't walked a day or an hour in my shoes. You don't know what it's like. You're hearing what it is for me. You can hear it in my voice, how passionate we both are about this.

Like I said, you go to these agencies and ask them what they need as well, but you need to get comments from the family members too, because families are so much more important than the agencies and maybe schools or whatever the case may be. We're just two people, but two people who are trying to make a difference as much as we can for the enhancement of our children's futures.

Ms. Jan Hudyma: So I'll address it too. I work full-time. I'm a single parent. I have another child. So what I've started to do is look into—my daughter is looked after, before and after school, by a sitter. What I have to do is pay money out of ODSP to pay for that. That's what's going to happen in July. And I'm hoping somebody who's an EA, a young EA, who would like to work extra hours, if they work part-time at the school boards, casual—get them to do a couple of days and my sitter do a couple of days. That's basically what I'm going to have to do.

I have no problem using her pension for care for her, but it would be really nice if there were actually set programs to send her to, instead of piecemeal, that kind of thing.

Ms. Mitzie Hunter: Right. So the income that's coming in from the ODSP program, you're using that to provide support services.

Ms. Jan Hudyma: I use it to pay for services, yes.

Ms. Patti Zimmermann: It's supposed to be used for room and board, according to the government, but \$832 doesn't go very far. Where the heck in the world—or, say, Thunder Bay, for that matter—can you live for \$832 a month, with everything? It's not going to happen.

Ms. Mitzie Hunter: Okay. Can I ask one more question?

The Chair (Mrs. Laura Albanese): One more minute.

Ms. Mitzie Hunter: Just on the daily living, life skills, that's something else that you're recommending, that there are more supports for that. Is that something that both your daughters are actively involved in right now, and that you hope—

Ms. Patti Zimmermann: Right now, they're in school. They do daily living; they do all kinds of cooking, things like that. I know my daughter is not employable. I can't just let her go to Walmart and say, "Okay, be a greeter at Walmart." Who's going to watch her? She needs help when she goes to the washroom. Unless it's mommy or a care worker or a caregiver—she can't do it herself. She doesn't have the capability to do that—plus the mindset too, with the autism, you know? They're moderate to severe. Autism is very multiplex, and unless you're a doctor—and even some of them don't know everything. Every autistic child is totally different. Routine and continuity are very important.

The Chair (Mrs. Laura Albanese): Thank you. I will now pass the microphone to Ms. Jones.

Ms. Sylvia Jones: Thank you, Patti and Jan. I just want to assure you that we're all here on this committee, serving on this committee, because we believe strongly in improving the system. Have some faith that we are wanting to hear from you, and we're trying to learn from everyone, as we see the changes across the province.

I'm curious: Because of the ages of your daughters, I'm assuming you're going through the lovely DSO process. Is the school assisting you in that transition at all? Is there any involvement on the school board side?

Ms. Patti Zimmermann: Well, when you've done transitioning, they usually start it—now it's age 14. The school hasn't done anything. We were involved with an agency, the CAS, in the programs from the CAS. My worker was CAS and kind of introduced me to the transition program and to the DSO services. They had talked to the school and consulted with the school in regard to what they feel would be necessary and what they need to know—you know, comments and stuff like that—but, no.

Ms. Sylvia Jones: Okay, but in terms of the actual transition post-June—

Ms. Patti Zimmermann: No. They're doing a little bit of co-op, but again, co-op involves her going to the airport for a ride. Co-op involves her going to the hospital, although going to the hospital is not, to me, in the best interests of my child, but I guess that's what they feel. It's just getting her out and integrated into society—you know, things like that. But she doesn't go per se to, say, maybe do shredding of paper or taking telephone calls or dropping off files here and there in an office or something like that. No, she isn't capable of doing that.

Ms. Sylvia Jones: Okay. One other question: You make specific reference to the Lutheran Community Care Centre and Wesway, both of which we've heard of from other presenters here today. Are there any other day programs that you're aware of in Thunder Bay?

Ms. Patti Zimmerman: Possibly Avenue II, but again, for all of these day programs, there is a long wait-list in order for you to get in them.

1550

Ms. Sylvia Jones: Of course.

Ms. Patti Zimmerman: And like I said, unless you pass away or move away to another country or wherever, the openings are very few and far between.

Ms. Sylvia Jones: Yes.

Ms. Jan Hudyma: I think March of Dimes has something. However, it's the same with my daughter: You couldn't take her and leave her somewhere, even if it was fairly supervised. She needs somebody to really kind of watch her—not that she would run off or anything, but if somebody said, "Come with me," she'd go with them. Yes, she needs more one-on-one—or not even one-on-one, but just a little more supervision than some programs can provide.

Ms. Sylvia Jones: Quite frankly, that's what we're trying to grapple with because, as you well know, there is a whole spectrum, so we have to look at individualized programs and individualized services. To your point at the very beginning, that all of us deserve to have a quality of life, it's not all the same, but that doesn't diminish it in any way.

Ms. Patti Zimmerman: Some of the programs out there, like Jan mentioned—March of Dimes, and there might be some with the city programs—you have to have a worker go with you. Well, that's fine; I can provide my worker, but not for eight hours a day or six hours a day. If any kind of worker wants to stay, they want a very good wage, something that's comparable to what an educational assistant or an SSP in the Catholic school board wants, so you're looking at \$18 and up. Well, if you're only getting \$832 a month, tell me how far that's going to go.

Ms. Sylvia Jones: Are you looking at all at Passport, or is that a lovely waiting list too?

Ms. Jan Hudyma: We both have—

Ms. Patti Zimmerman: We have Passport 2, yes, but Passport 1 turns into Passport 2, and then the funding for that doesn't necessarily match up to what it should match up to. Right now we have Passport 1, and however it has been diagnosed from years gone by—it used to be SSAH, Special Services at Home—

Ms. Sylvia Jones: Yes, and then at 18 it flipped over.

Ms. Patti Zimmerman: —and then once they turn 18, it goes to Passport 1, and then once they turn 21, it goes to Passport 2.

Ms. Sylvia Jones: Right.

Ms. Patti Zimmerman: But like I said, the money doesn't always increase. It stays relatively the same, but the needs of the individual increase as well.

Ms. Sylvia Jones: Well, for one thing, they're not at school for seven hours.

Ms. Patti Zimmerman: Well, they're at a school and they're more—

Ms. Jan Hudyma: That's the problem, yes.

Ms. Patti Zimmerman: That's the whole problem there. There is really nothing for them. If your child is functioning—I'll say the three things—and can feed themselves, can wipe themselves or can talk, you're fine, but if they can't do any of those three, what happens there?

Ms. Sylvia Jones: Thank you.

Ms. Patti Zimmerman: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: Yes. Thank you so much for coming forward. I know it's not easy; I know your lives are not easy; but thank you for being courageous enough to be here and take this time.

Trust me, I want to again reassure you that we—or some of us, anyway—don't think the system is working at all.

Ms. Patti Zimmerman: It's not. The system is broken.

Ms. Cheri DiNovo: And clearly, what we're doing in this committee is to try to see how to make it work, so I want to assure you of that. Your stories will not be lost; your experience will not be lost. That's number one. What you've brought forward as issues, other families are grappling with too, so you're not alone in that at all.

You're experiencing one transition, which is the out-of-school transition, which is, again, troubling and not handled well.

The other transition, which I'm sure you've thought about, is down the road when you get older and your families get older. Have you thought about that at all? If there was one recommendation about that time, when perhaps your children outlive you—have you thought about that and what government should be doing to help you make sure that your children have a future at that point?

Ms. Jan Hudyma: My daughter is on the list for assisted housing, because I'm a firm believer that she's not going to live with me forever. I think it's a natural progression, whether you have special needs or not, that you move out of the house. I know that there are bound to be good places for her to go that she'll probably really enjoy.

So, yes, she's on a list, and by the time she's about 25, I would like her to be in an assisted-living spot. Lutheran Community Care is the spot where her name is placed on a five-year application, I believe it is. So, yes, I've definitely thought about it.

Ms. Patti Zimmermann: The same with me. She's on a list as well with Lutheran Community Care.

Ms. Cheri DiNovo: Thank you very much.

Ms. Patti Zimmerman: Thank you.

The Chair (Mrs. Laura Albanese): Miss Taylor, did you want to add something?

Miss Monique Taylor: Thank you so much for being here with us today and for sharing your story. I hear your frustrations. You're right. I don't have a child with a disability, and that's why I'm here: to learn and to see what kind of recommendations we can put forward to make it better for families like yourself. I really do appreciate your time.

I've heard, "There's a place here," or, "A place here." Have you had help with finding resources in Thunder Bay? I'm not familiar with Thunder Bay. Is there a resource place where you can say, "This person is going to help me to see what's there for my children"?

Ms. Patti Zimmermann: There really isn't anything like that that I know of in town. We just deal with Wesway and Lutheran Community. I have phoned them and talked to my workers and said, "What about this? What about that?" Again, if your child is more independent than what our children are, yes, there probably is stuff out there for them. But, again, like I said, our children need workers with them 24/7. Like I said, I can't just drop her off there and say, "See you in five hours, honey." It's not going to happen.

Miss Monique Taylor: No, no. I understand. What would your thoughts be on a transitional worker from the time of birth to the time of death, to make sure that there's somebody there to guide families through—

Ms. Patti Zimmermann: That's a perfect world, but we know we don't live in a perfect world.

Miss Monique Taylor: Well, it's recommendations that have to come from somewhere, right?

Ms. Patti Zimmermann: They used to do that. Apparently, Lutheran Community Care used to do that in the past. But, again, I don't know if it's because of a lack of funding; workers—I don't know how that has transpired. But they used to, in years gone by, go into the school system and help them make the transitions to various programs and things like that. But, like I said, they don't do that now.

Miss Monique Taylor: What has your experience been so far with the DSO?

Ms. Patti Zimmermann: Again, we're just on a waiting list right now. I phoned them, but they're, "No news is good news." They more or less tell me—I complain to the ED, and they're kind of like, "Okay, fine. We'll just write her name down." The ED hasn't called me back at all. To tell you the truth, I don't even know who the ED is of Lutheran Community Care. I know Daniel from Wesway. I've talked to him on various occasions. But, again, their hands are tied too, and I'm told that they're not allowed to advocate or lobby for any money, because if they do that, then they can lose the funding—again, this is what I'm told—that they already have now. So their hands are tied, too. Again, I'm not certain who has made those stipulations or not, but that's what I've heard.

Ms. Jan Hudyma: I've got to say, Lutheran Community Care was helpful. When I phone them, they'll give me some ideas. When her name went on the application, they were helpful with certain things. I did find community care access helpful. She doesn't have much to do with them right now, but for quite a few years, she did, and the nurse manager I had was very helpful with, "Do you need help with this, help with that?" So that was one spot that was good.

Ms. Patti Zimmermann: I deal with CCAC, the community care access centre, and there's an agency in town, Bayshore, so I do get home support for my child, or

respite, like three hours on certain days—things like that. They're good that way there, too. Then there's another agency in town. I'm not certain what the name of that agency is, but it's something like Comcare.

The Chair (Mrs. Laura Albanese): Thank you very much. I want to thank you both for presenting to our committee today. I want to assure you that all of us—each MPP here on this committee—believe that there is a need for a more comprehensive strategy. We're here to listen to what you need, to what your challenges are. We know there's a need also to better coordinate the programs and the services that are available in the province. That's why we have this committee. So we're hoping to make a difference in your children's lives.

Ms. Patti Zimmermann: You have this committee here now, and you've finished going through the whole province of Ontario—

The Chair (Mrs. Laura Albanese): We have an interim report due at the end of February and a final report due by the end of May.

Ms. Patti Zimmermann: Okay. So now does that information go to the MPPs here in Thunder Bay?

The Chair (Mrs. Laura Albanese): Yes, and Bill Mauro will be with us tomorrow, and someone from his office, I believe, is here today. But, in any case, he will be with us tomorrow. All MPPs are kept informed as to what we do.

1600

Ms. Patti Zimmermann: So you're various MPPs from around the province?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Patti Zimmermann: Okay.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Patti Zimmermann: Thank you very much for listening to us.

MS. BARB WENTWORTH

The Chair (Mrs. Laura Albanese): Our next presenter is via teleconference: Ms. Barb Wentworth. Hello?

Ms. Barb Wentworth: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon. How are you?

Ms. Barb Wentworth: I'm fine. Thank you very much for giving me this opportunity.

The Chair (Mrs. Laura Albanese): May I ask where you're calling from?

Ms. Barb Wentworth: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): We have up to 20 minutes available for your presentation. If it's shorter than that, we will have an opportunity for comments and questions. You may begin any time.

Ms. Barb Wentworth: Okay. I taught special education with the Vancouver School Board back in the early 1980s, while at the same time raising my three children. I'm very proud of all of my children, who have grown into warm and caring individuals—even Mark, who has managed, through a very difficult life, to maintain his sense of humour and whose favourite adage is “Be

careful.” I want to share some stories of Mark's journey through his life.

We met Mark in Vancouver when he was four years old and thought that we would adopt him. He would join a big brother who was eight years old and a young sister who was a one-year-old. When we realized the amount of care that Mark would need and the amount of future unknowns, we worked out an arrangement to become life-plan foster parents, not really foster parents at all but Mark's parents in every way, except that we would not take on the financial responsibility for his extra needs. His diagnosis at the time was cerebral palsy with a Parkinsonian-like tremor and a developmental delay.

We enrolled him in the local school kindergarten and after the first hair-raising morning, he was sent upstairs to a specialty program for autistic kids. We went through one crisis after the next, and several years later we moved to Toronto. His challenges continued and escalated.

When I had to have surgery for a major health problem, Mark went into a group home, and he has been living in a supportive living environment for many years now. Everyone involved in supporting Mark has been challenged.

Mark's ability to tell us what is going on with him is extremely limited. We would go along in a steady line and then, inexplicably, have a crash where he would lose skills. All hell would break loose with his behaviour. Then he would pick it up a bit, but never up to his previous functioning ability, and go along for a while and then crash again, losing skills and behavioural control. This continued as he slowly declined in his abilities, both cognitive and physical. The last crash came with a five-week hospitalization when he was 39 years old, where he lost his ability to walk and to move his body much at all.

For a short time, we had a team that included New Visions Toronto, where Mark lives, Surrey Place and CAMH dual-diagnosis/CAIR team. Things were very challenging and very perplexing.

Luckily, Mark was sent for genetic testing at age 40 and came back with a MECP2 diagnosis, atypical Rett syndrome. Finally, what had always been so confusing started to make sense. His symptoms lined up with those of Rett syndrome: reduction in hand skills, reduction in communication skills, stages of slow neuro-motor regression, extreme kyphosis and scoliosis—that's a curvature of the back—swallowing difficulties, peripheral vasomotor disturbances—that's excessive sweating and cold hands and feet—sleep disturbances, laughing-screaming spells, diminished response to pain, intense eye contact-eye pointing.

Many of these symptoms we had perceived as behaviour problems and had used behaviour programs including time-outs and psychotropic drugs. All of this was done with the best information we had at the time. He is now being successfully weaned off his mood stabilizer medication.

Now that you have a background on who this young man is, I want to walk you through how Mark experiences his day. I want you to understand what service cuts in developmental services really mean and why what you

are doing is vitally important in reducing very real suffering in human beings who have no way to effect any change for themselves. We often fail them and increase their suffering through policies that don't address their needs.

I wish that Mark and I were in the room with you because this is a bit hard to do without being able to see you. However, I invite you to join me. I want you to step into Mark's shoes and take a look at his life from what I imagine might be his perspective. I want you to get comfortable in your seats, and while I am finishing my presentation, do not move at all. Do not move your arms, do not move your legs, do not squirm in your chairs. You can move your head, but just sit still and see how it feels. Know that you cannot move until someone comes and moves you. It doesn't matter if you are uncomfortable, it doesn't matter if you are in pain, and you are incapable of telling anyone how you feel. This is one of the Rett symptoms that Mark has—a diminished response to pain. That means that he feels pain but he does not respond in ways that would be easily interpreted by us.

So here we go: New Visions is a great group home. The staff is responsive and caring. But this is what is happening after five years of no funding increases and the extra legal obligation to absorb a half-million-dollar pay equity requirement, all with no extra dollars.

Remember, don't move. Pretend you're Mark. Okay, so staff gets you ready for bed at 9 o'clock at night. You don't sleep through the night. In fact, you have been recorded as having over 300 instances of central sleep apnea in one night. That means that your brain forgets to tell you to breathe and you wake up terrified. You need staff to come in and move you if you are uncomfortable at night, and you have to stay in bed until at least 9 in the morning, when the day shift comes in for work. That's a long 12-hour night when you can't stay asleep, are physically hurting and are often startled awake in a panic. Bedtimes and wake-up times are predicated on when staff is available to do the work, not based on what would work better for your comfort, and there is nothing you can do to change that.

Now you are up and ready for your day; however, a staff person has phoned in sick and there is agency staff on. They don't know you. They don't know how to read the subtle signs of when you are in pain. You can't go out. One of your coping skills is to distract yourself from your discomfort. How much easier that is to do when you have an active life out in the community. But staff have chores to do; staff have increasing amounts of paperwork to do. You rely on staff for your quality of life, and those staff are continually stressed by having to do more and more with less. There is nothing you can do to make your situation better.

Are you still sitting still? Maybe you have an itchy nose? You just have to put up with it.

Sundays are a real problem. You really like to go to church; in this case, the First Unitarian Congregation of Toronto. You love to sing and you "la, la, la" with great gusto. Usually tears roll down your cheeks because the music moves you. Afterwards, people come up and tell

you how they really like to hear you sing. You love this community and are loved in return; however, staff doesn't come in early enough to get you ready to take Wheel-Trans to church. Mom has to spend \$30 a week to hire a cab to get you to church on time. This is not doable in the long run. You may lose this community because there are not enough financial resources to allow for sufficient flexibility. You may have to stay home. That makes you feel sad, and there is nothing you can do to change that.

You look and see a large plastic jar on the dining room table with a sign on it to collect Canadian Tire money to go towards the purchase of a van. Perhaps you think this is an embarrassing way to fund necessary transportation. One time, you took the New Visions van to go to Hamilton to meet with the Ontario Rett Syndrome Association experts, but the alternator broke on the way. Luckily, you got off the QEW and limped home, all the while wondering what the contingency plan was if CAA had had to tow the van. I have never heard of a CAA wheelchair-accessible tow truck, and New Visions has had to sell off vans to try to reduce operating costs due to the five-year freeze in the budget.

If you are sick and have a fever, you have to take the TTC bus up to Bloor to see your family doctor or get wheeled up many blocks to St. Mike's hospital because New Visions can't afford to buy and struggles to keep old vans in good repair because transportation is not in the budget. They are doing the best that they can. And Wheel-Trans is increasingly busy, so it's another stressor in the system. There is nothing you can do about this.

You really like to go home to see mom and your sister, but mom needs to find a way to get you out of your wheelchair so that you can stretch and get freshened up. Mom was happy to get a donated ceiling track and lift; however, to install the track cost \$350, to fix the lift cost \$424, and to buy a tilting bed, which you need, was a bargain at \$300. That's over \$1,000, and the wheelchair ramp that was put in a few years ago was approximately \$700. All this is funded through mom's line of credit.

Are you still sitting still? Remember, you need someone to come and reposition you and you have no way of telling them what you need.

You like to help in the kitchen and watch what's cooking, but there has been no increase in the food budget in the last five years. That makes it hard on the front-line staff who do the shopping. There is nothing you can do about this.

Because Rett syndrome may eventually have a genetic fix, you are hopeful that the researchers can keep on working. It's very exciting that studies with mice have shown that the mice actually can get much better. Wouldn't that be wonderful? A new problematic development means that the Ontario Brain Institute now requires a one-third match of funding from the host institute or there is no grant. If there are no grants, there is no lab. You would prefer that your researchers spend their time doing research and your front-line staff at your group home spend their time working with you. Fund-raising for necessary operating costs is like gambling,

and you suffer the loss, because everyone is out looking for big dollars from the same sources, pushed there by a government that refuses to understand that these dollars mean the difference between a tolerable life and one of misery.

1610

You are an adult now, and you need a substitute decision-maker for medical decisions. You have to go to the Consent and Capacity Board to ask that your mom can sign on your behalf. The Consent and Capacity Board is very formal. They send a lawyer to represent you, but the lawyer has no background at all in people with DD and probably has never spoken with someone like you. At the hearing, someone says hello to you and then ignores you for the next two hours while they are going through their processes. Mom tries to be subtle and keep you amused and reassured. For a process that is there to defend your human rights, maybe some accommodation and training on how to include someone with DD would bring a little more humanity to the process and make things easier.

Are you still sitting still? Uh oh; you just got a cramp in your leg. Better use whatever coping skills you have, because someone has to notice that you are in distress and guess what the distress is about and then do something about it. Until then, the reality is, you have a cramp in your leg and no way to do anything about it.

Because mom has to make complex medical decisions on your behalf, she has to have access to a team that can help come to an agreement on the best way forward for you. Support is critical to reduce stress for the decision-maker and prevent mistakes. A Rett syndrome clinic has been opened that is a model for good support and responsiveness. As an adult, you do not have access to that clinic; it's for children. The one Rett syndrome doctor in Toronto is challenged with too few resources, like not having a secretary. Listen to this: You had an appointment in November 2013; the next available regular appointment with this Rett specialist is February 2015. The system is under-resourced in so many ways, and there is nothing you can do about any of this. You are totally reliant on others.

So while sitting perfectly still and knowing that you cannot move, without someone realizing that you are in discomfort or pain and being available to move you, let me tell you this: If we really were able to live in Mark's shoes and to have some idea of his challenges and their impact on his life, we would make different decisions about how we provide support to him and others living with disabilities. I credit Dr. Elspeth Bradley from Surrey Place for her teaching about trying to mirror what a day is like for many people with developmental issues. To me, it is the best way to feel the challenges and the discomforts that are a reality for those we support.

Quality of life is not just a measure of happiness, involvement and engagement. There is another level to quality of life that deeply concerns me: That is the unimaginable, lonely depth of despair that is experienced when you cannot articulate your pain, both physical and

psychic, and when you have absolutely no capacity to effect change for yourself. Therefore, your experience of being cared for absolutely depends on adequate funding for the people who look after you and adequate funding for your living environment.

I have given you the challenge to sit still for a set period of time, knowing that you can't move, that you need someone else to recognize and respond to your need. Then imagine that, day in and day out, every day. This is just one example of the many ways people are vulnerable. Explore this as much as you can as you go about deciding on a future direction for government policy so that you can truly appreciate the impacts of your decisions.

I have attached an OASIS operating pressures survey from July 2013 wherein agencies supporting people with special needs report that existing group homes are cutting staff hours and eliminating positions and gapping and closing programs and increasing the number of clients without additional resources. This is a recipe for disaster, and it is already happening. I have also attached a letter from Mr. Andy Rotsma, executive director of New Visions Toronto.

Here are my concerns: that you will rob from Peter to pay Paul, starve existing group homes, either to save money or so that you can open new ones. We have a moral responsibility to do better than that. The ramifications of the five-year budget freeze are already being felt. That has to stop. All the cuts and/or freezes have direct, negative impacts on my son's life, and he is totally reliant on what we provide for him.

I'm concerned that staff will leave the profession or go on strike due to lack of adequate wages. In fact, contracts are set to expire on March 31 of this year. That's just plain scary.

I'm concerned that burned-out, under-resourced and rotating staff will cause my son to suffer extraordinarily.

I'm concerned that governments will continue to mandate important policies that take money to implement and then not provide that money; for example, pay equity, new quality assurance requirements, new mandatory training for staff and new fire marshal requirements for automatic sprinklers. All this is to come out of an operating budget that has not increased in five years.

The worst for me is that governments do not have a realistic appraisal of the efficacy of fundraising to cover necessary operating costs, preferring to offset their own obligations instead of providing adequate financial support. It just doesn't work.

Remember, the experience of being cared for and how you experience that care is absolutely dependent on adequate funding.

Mark's favorite adage is "Be careful." He says it all the time. It is his statement of concern and caring. I think he means: "Be careful. Don't hurt yourself. Be careful. Don't hurt me. Be careful with life. It is a precious gift."

So I say, please be careful when you make your recommendations to the House. Please know that people with developmental issues are suffering. They are suffering along with the people who love them and must wit-

ness the courage with which they must live their lives. Find your courage. Don't fail them. Be careful.

The Chair (Mrs. Laura Albanese): We thank you for your presentation. We have about a minute and a half for each party to make comments, and we are to begin with the Conservative Party. Ms. Jones.

Ms. Sylvia Jones: Thank you, Barb. I have a question. How long has Mark been living with New Visions Toronto?

Ms. Barb Wentworth: About 15 years.

Ms. Sylvia Jones: And how was that process when you went through that? Because, as you probably know, there have been some changes with the DSO and that process. I'm curious as to how your transition was 15 years ago.

Ms. Barb Wentworth: Well, I went in for brain tumour surgery, so I don't remember it at all. Because he was a governmental ward when he was a kid, he just went into a children's group home and then stayed there and finally moved over into New Visions, which is a really appropriate placement for him. I didn't go through what natural parents go through with having to go on waiting lists or do any of that. I can't really comment on that.

Ms. Sylvia Jones: So your transition was as a result of a crisis, really? That's how the placement occurred.

Ms. Barb Wentworth: Yes, it was. Yes.

Ms. Sylvia Jones: Okay. Thank you, Barb.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo.

Ms. Cheri DiNovo: Yes, Barb, I just wanted to say thank you for your presentation. It was thought out; it was beautiful. It gave us an insight for a second or so into what you and your son are going through. I want to just reassure you that we have heard similar stories from many parents across the province, that you're not alone and that we here are committed to making an absolute difference and that I hear very clearly that funding is one of the ways in which we can make a difference. So I just want to thank you for everything you do.

Ms. Barb Wentworth: I—

The Chair (Mrs. Laura Albanese): Yes?

Ms. Barb Wentworth: I have a real problem with the whole issue of fundraising for everything because that seems to be the—"Well, if we don't have enough money, we'll just get everybody to fundraise and that'll take care of it." It just doesn't work. Using that as the way forward or the way to presume that we can support these individuals isn't going to work, and it just puts more stress on the whole system. A lot of what I am doing is dealing with the crisis with my son's personal life and his health issues. I don't have time to kind of get involved in all of the other things, but I do know that that is one issue that just puts incredible pressure on, and it means that it's a crashshoot whether you're going to get it or not.

Ms. Cheri DiNovo: I agree. Thank you.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: Thank you very much, Barb, for your presentation. In your presentation, you shared with the committee your concern dealing with the Consent and

Capacity Board. So can you share with us in terms of your experience, particularly with your son, how do we improve that board? Because obviously your son is not the only one who will be needing that support, and because you commented that there are lawyers with no background or knowledge about people with DD. Can you recommend or suggest to this committee with respect to that board and making sure the legal counsel for that board and the lawyers have some knowledge and skills to support yourself and your son in the future?

Ms. Barb Wentworth: Well, I think the first thing is that it took me over a year and help from many people to try and figure out how to even get before the Consent and Capacity Board, so there's not a lot of good information about how to go there. I'm still not clear. I think if you're a parent and it's your child, that when they're children, you just sign on their behalf. It becomes very problematic if you have any kind of clinical research trials or anything that needs a consent with an adult.

1620

I think the background thing is that everyone has the right to speak on their own behalf and sign on their own behalf, so when you have to give that up—I'm not sure whether I'm the only parent who has to go through that, because I'm [*inaudible*].

I think that a lot more education, I think that some in-house training—and for Mark to sit there for two hours and not understand the process. I understand that there are legal requirements to be done in this type of a process, and it's a serious process, but I also think that there needs to be some kind of accommodation so that people with a developmental disability who are going through that process have a bit more support than what they do.

Ms. Soo Wong: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much once again for sharing your story, your experience, and for giving input to this committee. It is truly appreciated.

Ms. Barb Wentworth: Do people who present to this committee get a copy of the report mailed to them, or do you have to go through some other process to get that?

The Chair (Mrs. Laura Albanese): I believe that that's something that we will need to discuss with the committee, but if you will keep in touch with the Clerk, Trevor Day, I am sure that there would be no problem in providing you with a copy of the report.

Ms. Barb Wentworth: I would really appreciate that. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Mitzie Hunter: Madam Chair, I wanted to see if the committee would agree to us exploring the opportunity, given that we're in Thunder Bay—I was quite moved by Patti and Jan's very practical presentation and recommendations about how they are navigating their own community. They seem to have received good supports from the Lutheran Community Care Centre, which is located right here in town. It services the northern Ontario region. If it is at all possible, with the talents that we have in the room, with our Clerk and his team, to

have them come here, because we do have time in the afternoon tomorrow, would you be open to that? It seems like an agency sort of juggling lots of things, and maybe it can give us some insights and perspectives.

The Chair (Mrs. Laura Albanese): If the committee members agree, what I would suggest is to have our Clerk perhaps phone this afternoon, while we're listening to the next presentation, and find out if there is any availability on their part to come and see us tomorrow afternoon. Ms. Jones?

Ms. Sylvia Jones: Or leave it open to them, if it is appropriate, for a site visit—

The Chair (Mrs. Laura Albanese): Or for a site visit.

Ms. Sylvia Jones: —because we do have that window.

The Chair (Mrs. Laura Albanese): Okay.

The Clerk of the Committee (Mr. Trevor Day): How long a presentation are we inviting them for?

The Chair (Mrs. Laura Albanese): How long a presentation are we inviting them for? The regular 20 minutes? Yes. Well, we have the flight to Moosonee tomorrow to deal with as well. Yes, let's see if we can accommodate them; if they can come here, it would be great, and if not, we'll inquire about a site visit. Thank you.

MS. CONNIE HARRISON

The Chair (Mrs. Laura Albanese): We'll move on to the next presenter, who is also joining us via teleconference. Connie Harrison?

Ms. Connie Harrison: I'm here.

The Chair (Mrs. Laura Albanese): Yes, hello. Good afternoon. How are you?

Ms. Connie Harrison: I'm fine.

The Chair (Mrs. Laura Albanese): And where are you calling us from?

Ms. Connie Harrison: I'm calling from Toronto.

The Chair (Mrs. Laura Albanese): We are ready to hear your presentation. You will have up to 20 minutes to speak.

Ms. Connie Harrison: All right. I'll try to discuss a little bit about how we got here and where we're at right now and what we hope for the future, because my son is aging out of the system right now. He's aging out of the children's system.

The Chair (Mrs. Laura Albanese): That's fine. Thank you. You may begin any time.

Ms. Connie Harrison: All right. I'm Connie Harrison, and I'm the mother of Boris Cibic. He was born in 1993. Even as a little boy, he was aloof and he didn't really make a lot of eye contact. Finally, someone said they thought he had autism.

He was diagnosed, first of all, by a medical doctor, but according to the rules then, you had to have a psychologist diagnose him, to get the care, the money or the help, so we had to go to Surrey Place, which we used to call "squirrely place" back in the day, because a lot of

them really blamed the mothers and things like that, and called the mothers cold and aloof.

Back in those days, it was pretty hard getting services, and a lot of the services were pretty bogus, like the behavioural therapy, which turned out to be a joke. Getting daycare spaces was very difficult. It was horrible.

We've progressed since then, but my son's autism is severe. He's non-verbal. He stims a lot. He has pica—does everybody know what pica is?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Connie Harrison: Okay. Anyway, he's pretty aggressive—very aggressive—and his doctor was saying, from very early on that he needed to go to a group home. I kept fighting it and kept fighting it, even though he was getting worse and worse, except the process to get to a group home was basically through one of the children's aid organizations, and they would just shame you.

Finally, we had to go that route, going through children's aid, and it was like, "Oh, you're this horrible person, putting him in the group home." It was only later on, because they were trying to get us to make him a crown ward, that one of the MPPs back in the day, Marilyn, helped us to get services without that sort of thing.

He's been in a group home since he's been about six. He was originally in one in Toronto, and then there weren't any more spaces in Toronto as he got older, so he had to go north of Toronto to a community—well, I'm going to say the community: Barrie.

So he's up in the Barrie area, and his family is always trucking up there to see him. We're on the road a lot to visit, and we feel sad that we're not close, because we wish he was closer, but the fact is that group homes are far away for many families—not just those who live in Toronto, but those who live in other places around the province, because there aren't that many group homes.

He's also in a group home where he's probably one of the older guys there, because there's nowhere for older ones to go. People seem to have a notion that autistic kids stay that way forever, and they don't think that they'll need somewhere to go. There are very few places for our people to go, especially the ones with high needs. It's also hard for them to have opportunities in the community. It's hard for them to have good schooling. The whole issue up in Barrie with the blockers was an example of a complete breakdown in communication between parents and the school boards. Thankfully they've addressed that issue.

I'm just saying that I'm getting on in life. I'm 58 years old. I have two children who are non-autistic, and they're working, and they're going to be there for Boris when I'm gone and fight for him as I've always fought for him. I guess that, as a mother, what I really want to know is, what are we going to do? I know people want to spend a ton of money on these therapies. Frankly, I don't see any scientific proof that they work.

All I can say is that we need to put money into group homes and other facilities like that. We need to put money into education, so that kids can have good classrooms for themselves. Forget about inclusion, because if

you're not going to have real inclusion, don't even bother. Good classrooms serve our kids so that they can be who they are. Also, we need to make sure that parents who are keeping kids at home get every bit of support that they need, so that they don't burn out, because a lot of people are keeping kids at home, and they're burning out quickly.

My son mentioned this to me earlier—he's at work—and he was saying to maybe make some kind of a deal with private groups that are offering certain services to help parents fund these things if they can't afford it, because some parents can afford it and some can't afford different things.

If you're going to put more money into autism, you're going to have to make sure that the people who look after our kids are qualified, because right now I'm seeing a lot of sad sacks—people who have really poor educational qualities. They go to these diploma mills, they come out, and they work with our kids for very little wages. You're going to have to pay good wages, and you're going to have to make sure that people are properly educated to look after our kids, because this stuff with hiring somebody who's just a PSW is not good enough, especially when they're having to restrain a lot. Things are going to happen that are bad if you've got people who are not trained properly doing constant restraints.

I don't know. I could go on and on and on, but I don't see any magic cure coming down the line for these kids. I just don't. All we can do is make them comfortable and keep them safe and as happy as possible in the community. That's going to require a political will that I haven't seen out there for quite a while. I have not seen that will.

1630

A lot of people just avoid us like we're the plague and vilify our children, as was done in Barrie last year, calling them monsters. What can I say? It has become a "them and us" kind of attitude, and I don't like it. I'm hoping, whatever this committee comes out with, that they're going to realize that you need a political will, you need to respect people with autism, and you're going to need to put money into paying to see that they are properly looked after.

My son had an iPad stolen. His belongings are like he's nothing, like he's a nothing person.

I get scared. I was sick recently, and I was frightened to die, because I want to keep alive to fight for my boy. I've been fighting now for 20 years. Occasionally, we see rays of light; we see some politicians who care. I wish all of them cared. They don't understand the struggle we go through, and this is not just with autism, but it's with other developmental delays. It's very, very sad, and it's mainly shame and blame the parents. We have to go begging for what the kids need, and it's more shame and blame, calling our kids bad names. Yet everybody talks about inclusion. I just wish people would do what's right, put the money there and start doing things that are right for the kids.

I don't believe in institutions, okay? I really don't, because that's not really good. But in some cases, you're

going to need to have them, because there are people who are hard to serve, and it is true. When you do have these institutions, make sure they're safe and secure, and you're hiring people who are not horrible people, like what happened down in London, Ontario. You have to have a high standard for our kids.

Maybe I'm asking for the moon; maybe I'm asking for too much. But I really want to see—I would actually like to see autism in its own ministry, and get away from having it a little bit in health, a little bit in Comsoc, a little bit in education. I would like it in its own ministry, because I'm tired of us being the orphan child in Ontario. Everybody is scared of us—the politicians, because we're going to ask for money to make things better for our kids.

I guess I'm going to conclude it by saying I don't know what kind of world Boris is going to be seeing in the next 10 or 20 years, if all of you guys and your various parties can come together and figure it out. But there has been a lot of lost opportunity over these last few decades for our kids, and I don't know what Boris has to look forward to.

I guess that's all I can say. Please realize that for good staffing, you're going to have to pay for it, and for good care, you're going to have to pay for it. The kids grow up; they're not kids forever. People need to see it and treat it like it's a health issue, not like it's some public shame.

The Chair (Mrs. Laura Albanese): Thank you very much for your open, frank, touching presentation. I will give my colleagues the opportunity to ask some questions. We'll start with Miss Taylor.

Miss Monique Taylor: Good afternoon, Connie. Thank you so much for joining us today. I realize that the issues that you and your son have to face on a daily basis are not easy, and then to have the energy and the strength to come here before us today and to give us your time and speak to us to educate us with the difficulties your family faces is really important. We're very thankful for that.

Connie, I'm just curious about what your thoughts are on the DSO, because you're right in the middle of that process now, I would take it.

Ms. Connie Harrison: A behemoth. Sorry. I'm speaking my mind here.

Miss Monique Taylor: What did you say? I'm sorry, I missed it.

Ms. Cheri DiNovo: A behemoth.

Ms. Connie Harrison: A behemoth.

Miss Monique Taylor: Oh, yes.

Ms. Connie Harrison: I wanted one-stop shopping, and what I got was Godzilla.

Miss Monique Taylor: Right. You know what? Thank you for that, because we're definitely hearing that from pretty much every presenter that has been before us.

Ms. Connie Harrison: That was the one [*inaudible*] told him what we wanted. Oh, my God.

Miss Monique Taylor: Like I said, you're right. We've definitely been hearing from many presenters that

the DSO just isn't working like it should be working and families are still struggling—

Ms. Connie Harrison: Before it was a crazy quilt, and now they give us that.

Miss Monique Taylor: Yes. Thank you again for sharing with us. We hope that this committee will be able to make recommendations to make life easier for you and your family.

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Soo Wong: Thank you, Connie, for sharing your experience with the committee, and your passion on this—

Ms. Connie Harrison: Soo, you know Boris. You helped him get an eye doctor back when he was a baby.

Ms. Soo Wong: Oh, this is a small world.

Ms. Connie Harrison: It was the eye doctor over at East General—because his tear duct wouldn't open. You remember.

Ms. Soo Wong: Yes. Thank you for reminding me, and thank you for everything you do for your son, as an advocate for this piece.

Ms. Connie Harrison: Thank you. It is a small world; it's very small.

The Chair (Mrs. Laura Albanese): Soo can't get over it, from her expression. I guess she's going back in time.

Ms. Connie Harrison: I have a memory like a steel trap, by the way. Even if it was 30 years, I would remember.

The Chair (Mrs. Laura Albanese): That's good. Ms. Elliott.

Mrs. Christine Elliott: Thank you very much, Ms. Harrison, for your presentation. I think we're all hearing the frustration in your voice. I can only assure you that the goal of this committee is to make sure that your sons and daughters—whether they have autism, a developmental disability, dually diagnosed—have a chance to have a life like everybody else. That encompasses housing issues, employment issues, educational issues, social issues—just being able to live a life like everybody else.

The bottom line we are hearing from parents is that because of the way the system is set up now, their children don't even have a chance at the most basic things that we take for granted.

So please be assured that we are very committed to finding some solutions that are going to allow that to happen and to make sure, in your case, that your son has a chance at a happy and productive life.

Ms. Connie Harrison: Thank you.

The Chair (Mrs. Laura Albanese): Thank you, again, for your presentation. Have a good afternoon.

Ms. Connie Harrison: Should I just sign off now? Is there any more?

The Chair (Mrs. Laura Albanese): No, that would be it.

Ms. Connie Harrison: I'll get a copy of the report?

The Chair (Mrs. Laura Albanese): Yes, our Clerk has noted that.

Ms. Connie Harrison: Thanks so much, everybody.

The Chair (Mrs. Laura Albanese): Thank you.

MR. IVAN SOLANO

The Chair (Mrs. Laura Albanese): We have one last presenter for today, via teleconference: Ivan Solano. Good afternoon. How are you?

Mr. Ivan Solano: Good afternoon. I'm fine. How are you?

The Chair (Mrs. Laura Albanese): We're all pretty good, thank you. Where are you calling us from?

Mr. Ivan Solano: I'm calling from [inaudible].

The Chair (Mrs. Laura Albanese): Sorry. Could you repeat that?

Mr. Ivan Solano: I'm calling you from Toronto. I'm from the University of Toronto.

The Chair (Mrs. Laura Albanese): Oh, okay. Sorry, the audio was not very clear and we had not understood.

Mr. Ivan Solano: Would you like me to change phones?

The Chair (Mrs. Laura Albanese): Are you on a speakerphone?

Mr. Ivan Solano: Yes [inaudible].

The Chair (Mrs. Laura Albanese): It may be better, because it seems like you're cutting out from time to time as you're—

Mr. Ivan Solano: Oh, is it? Do you mind if I give you another number?

The Chair (Mrs. Laura Albanese): Yes, that would be fine. Just give us one second. We're consulting our technical team.

Mr. Ivan Solano: Okay.

1640

Ms. Soo Wong: While we're waiting, can I ask a question?

The Chair (Mrs. Laura Albanese): One second. Yes, so while we're waiting, Ms. Wong has a question. Is that a research question?

Ms. Soo Wong: A research question; that's right. The witness Barb Wentworth: In her presentation, she talked about the Consent and Capacity Board. I'm seeing some consensus among members here—I think we need more information. So if we can get more information about this board, the type of staff working for this board, as well as the training. I'm hearing about the whole issue of the knowledge piece of these individuals working for this capacity board, and the access, because it was very clear from this particular witness that the access piece is a concern, and the staff and the lawyers with limited knowledge of DD and what have you. I think if we could get more information about the Consent and Capacity Board, it would be really helpful.

The Chair (Mrs. Laura Albanese): Mrs. Elliott.

Mrs. Christine Elliott: I would agree. I think that was something that I had flagged as well. If we could also get some more information on supported decision-making as well, because I think that can play into it: to allow people to have more of a say in their own life decisions. While they may not be legally deemed to have the power to

instruct with respect to financial or personal care decisions, that they have a say in it directly.

The Chair (Mrs. Laura Albanese): Okay. I believe Mr. Solano is back online. Hello?

Mr. Ivan Solano: Yes, I'm here.

The Chair (Mrs. Laura Albanese): Okay. You'll have up to 20 minutes to make your presentation. If it's shorter than that, we will ask you some questions or make some comments on what you will present to us. You may start at any time.

Mr. Ivan Solano: Just to introduce myself, my name is Ivan Solano. I'm a physiotherapist by training, and I am currently doing my PhD studies at the graduate department of rehab science at the University of Toronto. My research aims to review accessibility in terms of usability contracts to prospective target users. But today, I am not speaking only as a physiotherapist and not just as an academic researcher, but also more importantly as an advocate for kids with learning disabilities, as a father of a child with a learning disability and as a person myself with a learning disability that continues to impact my work and studies.

I shall, just to guide you in my presentation, begin with a brief research background, if you don't mind, on Canada and the impact of learning disabilities.

The Chair (Mrs. Laura Albanese): Yes. I just wanted to ask you: Could you speak just a little bit slower?

Mr. Ivan Solano: Okay. Did you want me to repeat what I said?

The Chair (Mrs. Laura Albanese): No, no, we understood. It's just that because of audio purposes and the way it's coming through, if you speak just a little bit slower, it would be better for everyone. That's all. Thank you.

Mr. Ivan Solano: Okay. I was just thinking of the time. Thank you.

So I shall, again, begin with just a brief research background on the impact of learning disability here in Canada for kids and adults with learning disabilities. Then, I will move on to the real implications for kids with learning disabilities and families with learning disabilities.

Research is showing that kids with learning disabilities are unique and provide the rest of us with a different way of perceiving our world that we normally take for granted. However, stigma continues to be felt, and lack of support, both from the community and, as well, from public offices. This puts a lot of pressure on us, the families and for many of us who are just starting to have families and whose incomes are not even there, and it feels like we are alone in this plight and clueless on how to navigate our way around for resources and help. Fortunately, we are in the rehab field, so we know our way around, and fortunately, my parents were both doctors, so they were able to guide me through this process.

What this meant for many, though, who are not in the same plight, have not been fortunate to get adequate support, is developing a high risk for negative implications.

These were shown in the studies by Mallett, Rosenthal and Keys, identifying learning disability as one of the factors that lead to family conflict and substance abuse in youth who are in Canada.

Also, according to the Learning Disabilities Association of Canada, Canadians with a learning disability are twice as likely to drop out of high school. About 30% of Canadian parents who have kids with LD also reported not being able to afford their kids' learning aids, which is also the same story in our case. As well, Canadians with LDs are two to three times more likely to develop mental health issues and overall poorer mental and physical health, compared to the general population.

A study by Hankivsky in 2008 showed that dropping out of high school does not only hurt the person and the family, but also impacts Canadian society and government in terms of health expenditures, social services, programs, education, employment, increases in criminality and lower economic productivity.

However, the LD impact obviously crosses beyond education and extends to the home. Baker Collins, in 2013, demonstrated the significant impact of childhood events, including struggles with LD in school and their social environment, that increases the risk to adult homelessness. When the homeless participants in the study by Baker Collins were asked what they think were the significant factors in their becoming homeless, 45% said, "Insufficient education." Instead of mentioning missing resources as what could have helped them, more participants indicated that knowledge of the available resources would have been very helpful.

On another aspect of focusing on the results of special education services as perceived by the street youth with learning disabilities here in Toronto, and how their learning was supported or not, Saldanha, in her doctoral study, highlighted the issues perceived by students and youth regarding special education classes, those being the stigma attached to it, and educators not being fully competent to address the learning needs of students.

On the other hand, the youth participants reported that the hands-on participatory and strength-based method of instruction were found to be helpful, as well as having peer support groups, life skills instruction, self-advocacy and, in a way, for the program to become invisible. This implies that the support program does not treat them as highlighting them as special in a negative way but, rather, as kids with different learning needs.

The current reality, which I will be exploring further, is also that there is still a gap in accessing and delivery of resources. A more recent study, by Patterson in 2012, demonstrated that difficulties associated with LD in childhood are potent risk factors for developing a number of adult health and psychiatric problems, including substance abuse.

On a positive note, though, in a 2012 study by Harrison, a program they developed called the learning opportunities task force for post-secondary students with learning disabilities, demonstrated lower dropout rates and a higher academic success rate.

This is what the research is showing, and it is very accessible to everyone.

I just wanted to highlight what it is for the average person. For the real issues that impact us families, as a group, these are some of the comments that I have gathered from my colleagues who have learning disabilities and who have kids with learning disabilities—and also, a desire from the family care office at the University of Toronto and from the focus group of parents with kids with learning disabilities.

One of the comments is that the Ministry of Education could issue clear guidelines on the 13 special education exceptionalities and perhaps even define them in a standard way. For instance, giftedness has no metrics associated with it; everybody comes up with their own definition. Also, people have what's called a disorder—ADD or ADHD—so they get more support in the schools. Many of them feel they are out in the dark, especially those classified as ADD or ADHD.

It takes way too long and too much intentional parent effort—financially, emotionally—for the administrative mechanisms to identify and finally put accommodations in place. So a child with special needs has to have their plans set up in advance, so that when they enter the classroom environment, the set-up for success is already there, and not the other way around, wherein the child experiences the difficulty and stigma, and then only the program starts in place. If there are other special-needs students in the class who have been identified and accommodated, then this often interferes tremendously with the success of the others.

1650

The Ministry of Education could also provide support for the executive functioning problems experienced by many people with learning disabilities and developmental disabilities by purchasing a demonstration syllabus of homework that will help educators, similar to Blackboard but available for different levels of schools.

The Ministry of Education could also coordinate a project to buy electronic textbook licences, so that students could access them from their home and their computer, as this can become very expensive. Dyslexic or blind students could also turn on text-to-voice features for these textbooks.

Class sizes are simply way too big, as well, in publicly funded schools, including Catholic schools. Average size across the board is meaningless in the context of the experience of an individual student who needs to be able to focus with minimal distractions, whether visual or auditory.

Necessary accommodations are also only available occasionally—certain hours per day or days per week—and dependent upon time-sharing of very limited resources, potentially across schools or even just within a school, based on the relative population of students with special needs. Special-needs kids need smaller class sizes.

It is also really hard for parents with kids to find social support for their kids. Many kids with developmental disabilities and learning disabilities have behavioural issues, but that doesn't mean that they cannot play.

However, there are limited opportunities for parents of kids with learning disabilities to have their kids play just like a regular child; they have to set up actual play dates for that, because the other kids wouldn't want to play with them.

Availability and access to comprehensive psycho-educational assessments are also an issue. These take too long, and by the time the kids get assessed a lot of other problems have already started. It would be better if it were very accessible and comprehensive. Also, the psychoeducational assessments offered in schools are only limited to what is already identified, and that doesn't help, because it only identifies what is already known as a weakness, but it doesn't comprehensively assess for strengths which could be used as a way and a strategy to teach the child.

The special OT, PT and ST services—or the occupational therapy, physiotherapy and speech therapy services—are also limited. The disability is not cured; it's permanent, and continuously evolving with the age of the child. The visits, as experienced by my wife, who is an occupational therapist in the community, could range from seven to a maximum of 20 visits, depending on the complexity of the condition. While the visits are geared to provide strategies to the caregivers, when the services end, the caregivers are not equipped with the appropriate skills and knowledge to continue to remediate their own child intervention, long after the PT, OT and speech therapy services have ended.

Also, educators need more training in how kids with developmental disabilities and learning disabilities learn, because we are not the same across the board. It is different, and they cannot just focus on the weakness. They have to give us the benefit of the doubt that we are not stupid or slow.

As a person, as an adult and, lastly, as an adult with a learning disability, it is also difficult to access support from the university through accessibility services, just because my disability could impact my normal life. However, I have never asked for any—I have never required assistive devices for my regular life, such as communication, because I was able to compensate.

However, schoolwork is more mentally intensive, and that's where I'm asking for support. Because my disability impacts my regular life as well, I am not able to access funding or support such as special hearing devices.

I believe that this is it. That's all.

The Chair (Mrs. Laura Albanese): Thank you very much. The presentation was very comprehensive. I will turn it over to the government side and Ms. Hunter for some questions.

Ms. Mitzi Hunter: Thank you so much for your presentation and the energy and the passion with which you delivered it.

I was wondering about your comment about the demonstration learning tools and the need for more of those. You mentioned Blackboard as an example. Do you think that there is enough innovation occurring in this field to develop those types of learning objects for this group?

Mr. Ivan Solano: I can only speak for what's happening in the university level. Yes, there is, but I am not sure about what's happening in the regular school boards, the elementary or the high school level. I could speak to what you say, that yes, it's possible and it does help us, as university students, the support given in Blackboard. It's helpful, but I don't think it's really accessible for students in the middle and elementary school and high school years. I don't think the Blackboard has been developed that much yet.

Ms. Mitzi Hunter: Okay. And you believe that these types of tools and technologies could assist in learning?

Mr. Ivan Solano: I don't think it's what I believe. I think it should always be based on evidence. The ministry or the provincial government could always conduct a short-term study on this, because we do not want to just waste funds; that's very limited already. So it would be good to conduct—if it is effective, and then we could roll out and implement this program. It has to be evidence-based.

What is my experience is that we have been given too many assistive devices that we don't really need and are not helpful. There is not much evidence if it's really helpful. It's just that the people who are selling them to the schools are saying, "Hey, this helps," but then it just becomes another gadget that doesn't actually work.

I believe that the devices for programs that need to be implemented have to be based on evidence.

Ms. Mitzi Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Elliott?

Ms. Christine Elliott: Thank you very much for your presentation, Mr. Solano, and for the emphasis on the educational issues around children and adults with learning disabilities.

One of the things that we've heard is that all children learn differently. Some children are visual learners, some are auditory learners, and then of course there are particular needs related to children with autism. We've heard about children with FASD, and now thank you for the information you've provided us on learning disabilities.

I think one of the things that we need to take a look at—and you mentioned it—is the issue of teacher training. We expect teachers to be experts in all things, and I think that there probably is a need to provide teachers in the classroom with more information and support so that they can do their jobs as effectively as possible. We also heard about educational assistant training over the last couple of days. I think all of those are really important as we go forward. Along with your suggestions, we will certainly take them into consideration. So thank you.

Mr. Ivan Solano: Thank you. Just a point to what you mentioned: I think more than just the training, they need to learn to proceed within the way we do perceive our world, because there are teachers who perceive that providing extra support is a crutch, and I think that's an

obsolete framework. We need support not because we are helpless and we need a crutch but because it helps us. I think teachers, especially the older ones—many of the teachers who are not in their youth anymore are still in that medical disability framework. We are able to, but we need support.

Ms. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Again, thank you very much for your presentation. What particularly stood out for me is that you're speaking as somebody with a lived experience of a learning disability. We haven't had very many come forward who have spoken for themselves; we've had others speak for them. So I want to encourage you in that regard because I think there's a great need to hear from folk themselves who experience developmental disabilities of whatever—and yours obviously are not as severe as many of the others we've heard from. So thank you for that.

Second of all, just to pick up where Ms. Elliott left off, we definitely heard about the lack of training, though, for educational assistants, particularly where those on the autism spectrum are involved. I know that you're eloquent in saying to see the world through, in a sense, different eyes, but out of your research, are you going to be making specific recommendations of what that training might look like? Because I think that would be very helpful.

Mr. Ivan Solano: Yes. Despite the focus group at U of T, we are doing our own advocacy and will be making our own recommendations, yes.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. That's wonderful. Once again and finally, a last thank you on behalf of all the members of the committee and good luck with your research.

Mr. Ivan Solano: Thank you. I just wanted to speak to what was mentioned. I don't know; it might not be here—I think it's very challenging. That's why I still need support and I took longer than usual to finish my degree. But why I'm doing this, even though it's difficult, is because I wanted to show kids with learning disabilities and parents with learning disabilities and the government that we are capable and we are very much capable, that we cannot just be homeless or unemployed. We have more use to this society than what used to be expected of us.

The Chair (Mrs. Laura Albanese): And you have every right to a very productive life and a happy life. Thank you.

Mr. Ivan Solano: Thank you.

The Chair (Mrs. Laura Albanese): Bye.

Mr. Ivan Solano: Goodbye.

The Chair (Mrs. Laura Albanese): And we are adjourned until tomorrow morning at 9 a.m.

The committee adjourned at 1701.

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CONTENTS

Tuesday 14 January 2014

Developmental services strategy	DS-287
Ms. Carrie Groulx	DS-287
Mr. Greg Bonnah	DS-290
Ms. Helen Leask	DS-292
TIPES	DS-295
Ms. Jennifer Wyatt	
Dr. Jeff Sherman	
Mr. Mick Kitor	DS-298
Rev. Maggie Helwig	DS-302
Ms. Silvana Cacciatore; Mr. Brian Jacques; Mr. Ken Maclam	DS-305
Ms. Brenda Parris	DS-308
Ontario Association of Residences Treating Youth; Partners in Parenting	DS-311
Ms. Christine Rondeau	
Ms. Cindy Walker	DS-314
Ms. Marilyn Leiterman	DS-317
Sioux Lookout First Nations Health Authority	DS-319
Ms. Janet Gordon	
Ms. Diana Brammall	DS-321
Dundas Living Centre	DS-324
Ms. Martha Fox	
Mr. Geoffrey Shea	DS-328
Ms. Lois Hacio	DS-330
Ms. Patti Zimmerman; Ms. Jan Hudyma	DS-333
Ms. Barb Wentworth	DS-337
Ms. Connie Harrison	DS-341
Mr. Ivan Solano	DS-343

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DS-12

DS-12

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Mercredi 15 janvier 2014

Select Committee on Developmental Services

Developmental services strategy

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Stratégie de services
aux personnes ayant
une déficience intellectuelle



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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON
DEVELOPMENTAL SERVICESCOMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Wednesday 15 January 2014

Mercredi 15 janvier 2014

The committee met at 0901 in the Valhalla Inn, Thunder Bay.

DEVELOPMENTAL SERVICES STRATEGY

MS. SUSAN THOMS

The Chair (Mrs. Laura Albanese): Good morning, everyone. We are starting our second day of public hearings here in Thunder Bay. It's another beautiful morning.

We will start by hearing first from Susan Thoms. Good morning. Welcome to our committee.

Ms. Susan Thoms: Good morning to everyone here.

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes for your presentation. If the presentation is any shorter than that, that will leave some time for comments or questions on behalf of the members of the committee. You may start any time.

Ms. Susan Thoms: Thank you for the opportunity to present. My name is Susan Thoms. I am 63. I am one of many mothers my age and older who care for our sons or daughters with special needs, who live at home.

I am here because my 27-year-old son who has multiple needs has experienced discrimination in the school system, and we currently struggle to maintain an adequate level of funding to allow us to purchase the supports that he needs to ensure any quality of life.

The experiences that Steven has had and continues to have directly affect me and my family. My experience due to his many needs ranges from fatigue to unbridled love. At nighttime I may go to bed feeling overwhelmed with all the things that I need to do for him, but every morning I am greeted with a smile that lights up his room. Despite the fact that he needs daily help with every facet of his life, somehow Steven's amazing personality keeps me going.

There are so many things I want to say that it is hard to slow down in order to be articulate. When I very recently learned about this committee, my thoughts were, "Do I want to retell my story? No, not really." I reasoned that if I could connect with one person on this committee, my experiences could possibly lend themselves to making some real change.

Although I want to discuss our current needs, I feel it is important to begin by revisiting my son's school experience and the period known as transition. Although the early years were emotionally and physically draining,

my most difficult experiences were with the school system. From the beginning, we experienced a system that was not eager or prepared for him.

When I went to register Steven in JK at our accessible neighbourhood school, I was politely but firmly directed to register him at a school in town. Due to the unwelcoming reception, I complied. I enrolled Steven at a school the board of education directed me to. After two years, it was suggested that he attend yet a different school because there was an elevator there. I felt as though Steven's continuity of education, friendships and familiarity with his present school were ignored. Due to this, I again felt unwelcome, and I complied. In the beginning of his time at the second school, we were fortunate to have wonderful teachers.

As my son grew, plans at the board of education office also grew. I heard through the grapevine that the board was planning a segregated class for students who required special assistance. After not being welcomed by our neighbourhood school and then being persuaded into relocating to yet another school, we subsequently received a letter advising us that our school board was constructing a segregated classroom and that they had selected Steven for attendance in it.

I was livid. I was forced to take a stand. All along I had simply wanted him included and learning in a regular classroom. At this point, I understood that the school board was not educated or equipped to accommodate children with my son's needs. They were scrambling to try to set up a segregated classroom in an attempt to honour their responsibility to accept my son and other children with special needs, but with little in the way of resources or the know-how to include him in a meaningful way. They were simply viewed as hard-to-serve students—to fit into their current system; not as children embarking on their life journey, children needing to learn and enjoy what the school system offers most children. So much for the slogan "lifelong learning," at least as demonstrated by the decision-makers at the school board.

In the book *Changing Canadian Schools*, Marcia H. Rioux writes in chapter 3 about her idea that the education system is a system of social disempowerment. Ms. Rioux writes about four myths that she believes people assume about education: the myth of universality in education; the myth of equitable education; the myth of meritocracy; and the final myth, "that the structure of

the education system results in a social and economic system that ensures equality based on ability." I think my son's experience with our school system would easily be an example of these myths.

I again draw your attention to an article entitled "School/Family/Community Partnerships: Caring for the Children We Share" by Joyce L. Epstein. In summary, Epstein states "the main reason to create such partnerships is to help all youngsters succeed in school and in later life." Yes, they are students, but children first. School ends but life continues after the school door closes.

The point I am making is that partnerships are important at every level. None of us operate in isolation. In their decision to arbitrarily pull my son from his peers and isolate him, I was again not consulted. This time I reached out to the ARCH Disability Law Centre based in Toronto to help me. My gut feeling told me that my son needed the company of other children and that isolating him was not only not equitable but that it would be detrimental. Putting my non-verbal son in a classroom with other non-verbal students and/or children with behavioural issues would most certainly provide little in the way of growth opportunities for him or his peers.

During the tribunal hearing that ensued, due in large part to the help that ARCH provided, the board of education representative who attended the provincial hearing fell asleep during the hearing—a wonderful example of the board's level of interest in my son's placement.

Through ongoing advocacy, Steven was not placed in the segregated classroom. This does not mean he received an equitable time in school. Due to his multiple challenges, educational activities like being included in class outings did not routinely happen. Lessons were not routinely modified for him. Some teachers and some educational assistants were good about trying to ensure that my son was receiving modified instruction, but there was definitely no consistency.

I think I know my son pretty well. I know he loves people, he loves to be included and participating in activities. He brings out the best in those around him, given the chance for them to get to know him. He is not to be feared. He cannot harm anyone. He is an amazing listener—he's non-verbal. He is patient and open-minded, and the list goes on.

My beliefs lie along these lines: All people can learn and need choices; that differences are good—in fact, life would be boring without them; that children learn from one another, as well as from adults; that by segregating children with special needs, you are denying them the opportunity to learn, and that the world includes a wide variety of people and abilities.

If in life we shunt our more difficult concerns off to the side, they somehow wait for us until we have some even more pressing issues to deal with. I think everybody can relate to that one.

Isolating children who are developmentally delayed is a system I believe that slows the growth of all children and adults. A system of education that would allow a child to be segregated from his peers is not one that I

support. Not consulted or offered choice about placement, not being open to even trying to include Steven in a classroom, dismissing him as unworthy of enjoying the classroom experience that most children enjoy is discrimination to me.

One incident stands out for me from Steven's grade school time. Dropping off an item to his school one day, I discovered Steven sitting on a toilet unbelted and unattended. Keeping in mind that he is non-verbal, he has epilepsy and spastic quadriplegia, you might imagine my angst. I waited some time before the support person returned. Shortly after reporting this incident to the principal, I received a letter stating that if I wanted to visit the school I would have to request permission to come on school property—which I ignored, of course.

An incident like this would lend itself to questioning a system that would hire and keep on an employee who demonstrated this level of performance. This person was also responsible for assisting my son academically. Obviously, the expectation that my son learn to the best of his ability was not on the school board's agenda. I note this incident to highlight the myth of universality and the myth that education is equitable. One just has to be the parent of a child with higher needs to know first-hand that they are indeed myths.

The level of instruction that a student receives varies with each teacher they have. If you are a child requiring support, your education really depends on the knowledge and skill that your support person and the teacher display. Teachers work for the school board. Segregating children who come into the school system with special needs starts at the top. It is the system that dictates what will happen and the level of funding to make it happen. If children with special needs are to truly be given the opportunity to learn to the best of their ability, they need educational assistants who are skilled at helping them with their specific support needs—people who take their responsibilities seriously.

0910

When grade school ended, it was again presumed that Steven would attend a large segregated classroom in a local high school and not attend the high school that the rest of his peers and friends were headed to. After some deliberation, he was granted permission to attend the high school that his peers and friends were going to attend. The stipulation was that he could not attend any science or music classes. Steven ended up experiencing the support of some wonderful educational assistants and teachers, a few of which stand out from each school that he attended.

There were many bumps in Steven's school days. Despite them, I know that he misses all the people who took an interest in him, and there were many exceptional people. My thoughts are that in the end, Steven taught them, or at least allowed many people the opportunity to get to know him.

While these experiences are not current, I have been informed that the school system still operates on a deficit model, assuming that children are not competent.

We do not all aspire to be rocket scientists. I do not think we need that many. Everyone needs to have a meaningful place in society, and that starts with participating in the mainstream at school along with their peers and with the support to enable them to reach their potential, whatever that may be.

“Transition” is the term used to describe the move that students labelled as having special needs make from the education system out into the community. While the term “transition” generally denotes a smooth move, that is not generally the case, due to the very limited supports available to young people leaving the school system.

My son’s transition was abrupt and impersonal. One evening about a month before his exit from school, I received a telephone message advising me that Steven would be finishing school in June. I had been under the assumption that he had until the end of his 21st year to attend school. He was 20 when I received the message.

A number of major issues suddenly arose. Were we going to receive an increase in support dollars so I would be able to continue to work, and if so, how much and when? If increased funding were not forthcoming, and quickly, I would have to retire early.

Another very stressful time: I quickly discovered that I had to complete the paperwork required to access what was called Passport funding, and then I had to wait for a reply. I include this experience to show the level of preparedness that the school system demonstrated in our situation and to emphasize the amount of planning allocated to my son, who had been in the same school system since JK. It would have been extremely helpful to have had two ministries working together to help me plan a smooth transition for Steven.

Once we had the knowledge that Steven’s school years were ending, we were offered help by the Ministry of Community and Social Services to assist us in trying to obtain the funding that would allow us to purchase daytime supports.

I did not know if we would receive funding, or how much. I could not even begin to think about hiring anyone to cover the daytime hours that would allow me to continue working. I was forced to choose between financially supporting my son and my family or staying at home to do the daily support required to ensure that his health and well-being were met. I quit my job.

Funding was approved late in the fall. I immediately began looking for a suitable person to hire on as a daytime support for Steven so that I could return to work and financially support my family.

Since our initial receipt of Passport funding seven years ago, we have never received an increase in the amount allocated to Steven to purchase supports. As the years roll on, the need for some level of cost-of-living allowance to accompany the basic funding allocated for supports for Steven emerges loud and clear.

I currently have seven different people who do part-time support work with my son. I am confident that if I could offer a higher hourly wage, I would be able to attract and retain people on a more permanent basis.

Over the years, we have had dozens of people doing support work with Steve. Many people have stayed on only long enough to locate a full-time job with benefits and a higher hourly rate. Losing good people to agencies is an all-too-common occurrence.

When a scheduled support person is ill, moves on to take another position or is absent for any other reason, I must become the person who supports my son, which leads me to another issue that is a common situation for many of us who are caring for a son or daughter with special needs at home.

I recently received a letter from our Lutheran Community Care Centre, advising me that I had not used some or all of my son’s Passport funding. The letter went on to advise me that someone would be calling to offer us assistance around how this funding could be used.

I know how to use funding. I want my son engaged. If I have no one to do the support work, I have no one to spend the money on. I am the one to fill in. I am the person responsible for doing the administration work, but I cannot pay myself. I am grateful for the funding that we receive. I think that we use the funding wisely. I realize that many families do not have funding.

I can understand why this committee has been struck. There is an enormous need to overhaul the systems. I do not have many answers, but here are some ideas:

- (1) Stop the endless assessments and reassessments.
- (2) For people who have lifelong needs, grandfather funding for the supports that they require, and ideally ensure a cost-of-living allowance so they are able to retain their support system.
- (3) As an incentive for graduates of the PSW program who choose employment in a home-based setting, rebate a percentage of the PSW course for any individual who remains in a placement in a home setting for a minimum of a year.
- (4) Set up a benefit plan for PSW graduates who are employed in a home setting, allowing them to contribute to a choice of plans, i.e., dental, eye care etc. If the person pays for the entire plan, it could be tax deductible. This might attract more people into this occupation and help to keep them working in a home setting.
- (5) Set up some kind of a provincial pension plan for people who do PSW work and who are employed in a home setting—a plan that is portable and funded by what they put in. As a larger provincial plan, it would grow over time.
- (6) Set up a registry of qualified PSW graduates so that parents would have access to people interested in doing support work in a home setting. Set it up at the college.
- (7) Incorporate a mandatory course on inclusion at the faculty of education, rather than an optional course on special education—and I’m not really current, so I don’t know if that’s taking place.
- (8) Early on, establish and keep a circle of friends going for students who are developmentally challenged. This concept could be a priceless method to assist

countless young people throughout their school years and beyond.

(9) Consider subsidizing the private sector to build small housing units, the idea being that there could be some shared living space, some private space and shared support between the people sharing the building. Parents are willing to invest in housing for their children, but 24/7 care is prohibitive.

In conclusion, what happens when I am not physically able to take care of my son? Who will advocate on his behalf?

Steven was originally part—I don't know if I can read this—of a pilot project called Choices. Through this project, individualized funding was unavailable. I was not yet experienced enough to understand what a significant opportunity this was, or how important it could have been for my son. At that time, the request I made was for some help to connect my son with his peers, the children he was in school with. Steven's need for accessibility, combined with our location in the country, made connecting with his friends a challenge. If there's one thing I regret, it's not understanding the importance of individualized funding and requesting it for him.

At the end, I explain what meritocracy is, because I sure didn't know. The education system is structured and run in a way that is necessary for the continuation of the current economic and social systems.

Thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you for this passionate presentation. There is no time left for questions from the committee, but we want to thank you for sharing with us so intimately the story of your family and your son. Thank you for your suggestions. They are very much appreciated, and we'll take them into consideration.

MS. DERYLE BOND

The Chair (Mrs. Laura Albanese): We will now ask Deryle Bond to come forward. Good morning. Welcome to our committee. Make yourself comfortable. As you have heard before, you will have up to 20 minutes for your presentation. You may start any time you feel comfortable.

Ms. Deryle Bond: Thank you for the opportunity to address the committee.

I wasn't going to get emotional, because I don't usually, but after listening to Susan—my name is Deryle Bond. I'm the sister-in-law, advocate and power of attorney for Maisie Bond. Maisie Bond is 62 years old. She's a senior citizen with a pervasive developmental disability. Mentally retarded with personality disorders, bipolar, manic, multi complex support needs—these are several titles that have been addressed to her situation over her 62 years.

0920

Excuse me. I'll get it together here.

In 1995, Maisie was chosen to be in the pilot project for Choices individualized funding. At this time she

moved into residential living at age 43, having lived at home with her widowed mother until her mother was 83 years old.

Until October 2012, for 17 years, Maisie has lived a very full, functioning and happy life. She has been served very well by the system under Choices individualized funding. With the help of a planner/broker, we navigated through the system as changes came and went. Maisie lived in a family environment, working during the day at ARC Industries/Monty Parks Centre and living a normal, routine, day-to-day life with a family which included family outings, camping, mini vacations and simple day-to-day routines.

As Maisie has aged, it has become more difficult for her to keep up with the daily work grind, and at age 60, she retired from Monty Parks Centre after working there for 30-plus years. This development caused her residential model to change, requiring 24-hour residential care as opposed to part community placement/block funding and part residential placement/individualized funding.

Unfortunately, at this time she had a bout of ill health that required her to become hospitalized. When her medical problem had improved and she became stabilized and able to return to the community, we were told that there was no suitable residential placement for her. There were no family home placements or group home vacancies at this time. She had to live in the hospital. This situation lasted for the next six months. This was one of the darker experiences of her life.

The Chair (Mrs. Laura Albanese): Take your time. Take a breath if you need to. We'll wait.

Ms. Deryle Bond: At the end of six months in the hospital, she was offered a bed in a seniors' long-term-care home, Lakehead Manor. Having no other options, Maisie and family agreed to her placement in a long-term-care home even though it is another medical model, not a model set up to support her developmental needs.

As a transition from the hospital to long-term care, Maisie received a personal support worker to assist her to adjust to this new residential model. Her individualized funding through Choices is now being called transition funds for 30 days. We then had to negotiate an extension to 60 days, then negotiate an extension to the end of March 2014, and now will be submitting a budget from March 2014 to April 2015. These dollars did not automatically follow Maisie. The family had to lobby the system for 30 days, then 60 days, then the end of March, and finally submit a budget to the end of March 2015. What happened to the individualized funding that she has had since 1995?

Maisie is receiving a personal support worker three hours per day Monday to Friday and 16 weekend hours per month for recreation. These hours allow Maisie to help maintain the lifestyle that she has experienced over her last 20-some years. The support hours allow a personal support worker to assist Maisie on a daily basis to partake in the in-house daily programs at the manor; community programs outside the manor; help to educate the manor staff in the strategies that work in assisting

Maisie to stay balanced; help her to keep her personal things—for example, keep clothing in order, organizing, replacing, and helping Maisie to make appropriate choices; her recreation, attendance at hockey games—of course, Christmas is just past, and she went to the Santa Claus parade—Parade of Lights, Christmas banquets, bowling banquets and Special Olympic bowling on the weekends.

These are the necessary activities that Maisie needs to be assisted with to keep her balanced to live a normal lifestyle. Maisie does not have the mental ability or cognitive skills to handle these necessary daily skills for herself.

The staff at the manor is highly challenged with their present hours to just complete their present long-term-care duties. They were not allotted extra hours to handle Maisie's personal developmental needs. Family and staff have observed this to be true over the last six months of her placement in a long-term-care facility. Family can also attest to the fact that long-term-care staff do not have the adequate hours to complete their own duties. Maisie's mother was in long-term care from 1998 until her passing in 2003. We observed the same timelines that were not adequate then, and the system has not improved in that respect. Therefore, these areas of Maisie's life will go unattended, and she will slide into an uncontrollable situation, making her a danger to herself and others, becoming a crisis situation for everyone.

There is no guarantee of Choices individualized funding continuing. Funding is always tentative: maybe, maybe not. We're told that individualized funding no longer exists. Aging family members will limit the possibility of lobbying and negotiating support on her behalf in the future. There is the possibility that the Ministry of Community and Social Services will not share Choices individualized funding with the Ministry of Health, where Maisie has been placed by the Ministry of Community and Social Services. A group home is not likely as a placement because of the cost of the group home. It could be up to \$300,000 a year, as opposed to her current individualized funding of \$35,000 a year.

In conclusion, Maisie's developmental handicap is not going to change for the better or go away; it is there to stay until the end. Without this assistance in Maisie's daily life, she will slowly slide into an uncontrollable situation, making her a danger to herself and others and becoming a crisis situation for everyone.

Why is her support funding always on the line and in jeopardy? Why is the system becoming harder to navigate? When the Minister of Community and Social Services stated that funding for developmental services has had a 63% increase since 2003, where did Maisie's \$35,000 go?

Our solution for Maisie would be to see Maisie's situation be grandfathered, with her individualized funding through Choices in the amount of \$35,000 per year until her death, or put her in a group home at \$300,000 per year.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for sharing such an emotional story with the members of the committee.

We do have about three and half minutes for each party to ask questions. Ms. Elliott?

Mrs. Christine Elliott: Thank you very much, Ms. Bond, for coming and speaking to us today about something that is obviously very personal and very difficult to talk about. We've heard similar stories from other families.

What I'd like to ask you about is, has Maisie articulated to you what she would like or, if not, what would be the ideal situation for her, as far as you and the family are concerned?

Ms. Deryle Bond: She would be fine where she is now with personal support, with what she has now, because it keeps her balanced. With the staff from the manor and her personal support, she would be fine.

Mrs. Christine Elliott: So as far as you're concerned, it's okay for her to be living in a long-term-care facility at this point?

Ms. Deryle Bond: As long as she has personal support dollars, yes.

Mrs. Christine Elliott: Okay. But yet you can't get that securely funded; you're constantly having to negotiate it.

Ms. Deryle Bond: Correct. It probably would be there, but you never know that. I'm over 70, and her other brother is over 80 and not well. I mean, pretty soon, she's going to have nobody to advocate for her, and so everything will just go down the tubes.

Mrs. Christine Elliott: That certainly has been a concern that has been expressed by many family members, about what's going to happen when they're not there any longer to be able to advocate. So in all fairness—

Ms. Deryle Bond: So it would be this or a group home, but, I mean, forget a group home. You're not going to get a group home in Thunder Bay in the next 25 years.

Mrs. Christine Elliott: Are there any group homes for more senior people with developmental disabilities in Thunder Bay?

Ms. Deryle Bond: I don't think for seniors specifically. I think they're integrated in with the other group homes.

Mrs. Christine Elliott: But as far as you're concerned, there's really nothing any more suitable for her than where she is right now?

Ms. Deryle Bond: She's fine where she is, with her funding, but without funding—no.

Mrs. Christine Elliott: Okay. There's a question about whether she'll lose it at 65. Has anybody said anything to you about that?

Ms. Deryle Bond: With the Choices individualized funding, there wasn't an age limit. We just assumed that's—I mean, it's not a pension; it's not ODSP. It's her personalized funding.

Mrs. Christine Elliott: Okay. Thank you very much for being here.

0930

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much. Certainly, I just want to assure you that this committee has been struck and we're here to make things better. We've heard similar stories from other folk who have come forward at hearings. Some themes emerge, one of them being that dealing with a system that's very discretionary instead of entitlement, like health—she should be entitled to what's necessary for her to have a healthy life, and clearly that's not working. So I want to assure you that we're committed to changing it. That's number one.

Just a question about the long-term care: She spent six months in the hospital. When you look at the cost of that to the government, to us all, that is outrageous. To your knowledge, is this happening fairly frequently in Thunder Bay, that people are spending long periods of time in hospitals because of want of a bed somewhere else?

Ms. Deryle Bond: Oh, definitely.

Ms. Cheri DiNovo: So that points me to research again. I would love to know about alternate levels of care in hospitals. I think we've asked this before: How many people are in hospitals who have developmental disabilities and who are waiting for beds? That would be a very important figure to have.

Thank you very much.

Ms. Deryle Bond: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzi Hunter: Thank you, Madam Chair. Ms. Bond, thank you so much for sharing Maisie's story and for all of the work and dedication that you've done on her behalf over the years. As others have said, the purpose of this Select Committee on Developmental Services is to look at how we provide that continuation of support across a person's lifetime at different points and stages of life. Very important, and it's really stated in the mandate of the committee, is the cross-ministry support and coordination. We've certainly heard that today and it is one of our core mandates that we are seeking to improve. You've actually, in your very well-presented documents, which we have, illustrated a need to have better coordination between the Ministry of Community and Social Services and the Ministry of Health. We heard earlier about the need for the same with the Ministry of Education. We've received that information, and the intent is to make sure that we have better coordination so that there is not that impact on the individual in terms of their quality of life. I just want to thank you for your presentation today and to assure you that the committee is here to listen and to act upon these recommendations.

Ms. Deryle Bond: Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you once again for presenting to us.

Just a brief parenthesis for the committee members: We do have confirmation that the Lutheran Community Care Centre has accepted to come and present to the committee at 1 o'clock this afternoon. That's not on the agenda, but we will add them on if the committee agrees. We wanted to hear from them. They prefer to come and

see us rather than, I guess, us going to see them. We may be too many for the centre to handle. They'll be here at 1 o'clock.

MS. SANDI BOYES

The Chair (Mrs. Laura Albanese): We'll now call Sandra Boyes to come forward. Good morning and welcome to the committee.

Ms. Sandi Boyes: Good morning. Can you hear me?

The Chair (Mrs. Laura Albanese): Yes, we can.

Ms. Sandi Boyes: Okay. Thank you for giving me the opportunity as well to come and speak. My situation is a little bit different. We're all here for the same reason, I believe. Do you have my package in front of you, as well?

The Chair (Mrs. Laura Albanese): I think it's being distributed as you speak.

Ms. Sandi Boyes: Okay. In my package, I'm speaking on behalf of my son Thomas Boyes. He's intellectually disabled and he has low tone and balance. He's never been identified with a specific label, as we call them, which doesn't give him the opportunity for a lot of programming. I always have to advocate on his behalf. He's very high-functioning in certain areas—no label except for developmental disability. We've seen many doctors over his lifetime. He's 25 years old. He lives at home. He gets support through Passport funding only because he had Special Services at Home funding.

Thomas gets \$1,800 a year in support, which—I run out of funding. I don't ask for lots for him. I work full-time. I've worked in long-term care as a food service nutrition supervisor, and I've been in that position, working in long-term care, for 25 years. So I totally understand long-term care and the funding, because we never have enough for our seniors as well.

Going on with this, I did submit Thomas's wishes and goals, and they were done in 2008.

I don't have a problem with workers; I have a problem with funding. I used to pay my workers—I could do it for four hours a week.

Thomas likes to go swimming and bowling and to floor hockey. He competes a lot. We snowshoe. When he was younger, he was involved with Easter Seals; now it's Special Olympics. He has represented Ontario in snowshoeing competitions all the way to the nationals in 2011.

I like to keep him active. He works part-time and has been working three hours on a Wednesday afternoon for Petrie's Cycle and Sports, but he can't even ride a normal bike, even though he's not in a wheelchair or anything like that.

He's very outgoing. We go to all the hockey games. He knows a lot of people in Thunder Bay. I go to places—we were in Toronto at a Blue Jays game. Someone walked up to us: "Hey, Thomas. Thomas, right? You're from Thunder Bay." He walks up to everyone: "Hi, my name is Thomas." He's very social. I'm sure the people behind me know him very well.

I'm a very proud mother. I have another son who is 23 years old. He lives at home as well and has his own things that he does. He isn't as involved, so sometimes that takes away from other siblings at home. It's very difficult when you have a son who looks like you and I, until we have a conversation.

I have no private life. Everyone, I think, in Thunder Bay knows what I do, where I go, when I'm at bingo with my mom, when I'm at the grocery store, because when you phone, he tells you my number at work or wherever we are and what we're doing.

Anyway, onwards with this.

I have my own thing that I'm kind of saying. I wasn't even prepared to say all this stuff about Thomas, but with the help of the others who spoke before me, that gave me the courage to go on with that.

He also volunteers Thursday mornings at Lakehead University, at the field house. He knows all the Thunderwolves players, both the basketball and hockey players, and even the Staal brothers, when they come to work out in the summertime at the university. I mean, he knows a lot more things than I do in the community.

Anyway, to go on with this, I'm really disappointed in having to advocate all the time and be on the phone. Being that I work full-time, I'm burnt toast. I have an 82-year-old mother who comes to my house daily, because Thomas is at home during the day. He phones everyone. He needs the socialization. He needs somewhere to go daily. You know what? We don't want them playing games or watching TV and those kinds of things. That's what is putting kids in unhealthy situations: overweight, no exercise. Healthy living, socialization, all the things these young adults need—as soon as they turn 18, the system changes on them and we're fighting for every little thing.

In 2011, I had a two-day assessment saying, "We're going to provide funding for you for your son to be a normal 23-year-old." He's never going to be a normal 23-year-old, and, man, who am I fooling if I think he is going to be? I don't expect that of him. I just expect him to have his friends and to continue with that and be happy. He's very happy. He doesn't complain.

I just don't know where to go with this. Is there one go-to place? I have to phone and ask, "How am I going to get more funding? I ran out of funding." I have a continuous worker; I have lots of people who want to work with him, and I just can't. I used to pay my worker \$10 an hour, and she never even complained. In the past year and a half, I put it up to \$15, but that's to take him to swimming at night, because he goes swimming on Monday nights. Wednesday night is floor hockey. On Friday nights, it's either basketball that he wants to go see—the local Thunderwolves, ladies' and men's basketball—or it's hockey. I go to all the hockey games; I love hockey and stuff like that. But, jeez, I'm burnt toast. My social life is my son's social life. The time when I'm by myself is when I go to work as a supervisor in long-term care and I see all the long-term-care people that I'm trying to balance my budget for, to make sure I've got enough money to feed them.

Seeing these younger people going into long-term care—no, that's not the place for them. Yes, with the supports, because I see nursing staff, the PSWs—they don't have the funding to have the proper care for both our seniors and our special-needs children. For me, we need one go-to place that'll provide these services, whether it be dental, health care.

0940

I found out from my podiatrist, or whatever you call her, that my son could go and see someone about his orthopaedic shoes. He's been off balance for 25 years, seeing a specialist, but this orthopaedist said he has high arches. We found where to get funding for him to get these special insoles. He loves them, and he's on balance. It just took that one thing—but it took 25 years?

I'm not ignorant about the health care—but it's just the communication. The dental, the health care, the one go-to place, the socialization—where can we go? I don't want to go from phone call to phone call about my funding: "I'll transfer you to her. I'll transfer you to him."

I knew about this committee through Jerry Woods because I had phoned him. I don't even know the man—if you're sitting here. I've never met him, but I spoke to him on the phone, and he said this committee was here and, "Would you like to speak?" I said, "I don't know." But I guess that if we become vocal as parents, then maybe we'll get somewhere. It's just really stressful.

Putting these kids in group homes? Is that the right answer? That's expensive. Putting them in long-term care? It's expensive. Health care? Expensive.

If these kids could exercise and have a go-to place, somewhere where they're safe—where I'm at, there's PR Cook Apartments. That's a safe, secure building. We have a little café. They have an exercise room downstairs. That's at Bethammi Nursing Home, where I'm at, the Heritage. They have all these supports there for the seniors before they're moved into long-term care—because that's where they normally go. They have their meals together in the café. It's not institutionalized. But the waiting list to go into PR Cook is huge. So where do our young people go, and who advocates for them?

I just want to have the services streamlined and have a go-to place for parents for information-sharing and finding out facts about where we can get funding. I just heard today about Choices. I'd never heard about it. It's by talking to other parents who have young adults or even children that we find out from one another. We'll have a phone call.

Even the RDSP for my son—I never knew about that. We can invest a few dollars in that and he'll have something. He can do this until he's 49. It's help from the government, and it's helping the government, and they're saving. That's a win-win. Do you know how many banks I had to go to in Thunder Bay? And then they transferred me to Toronto because they didn't have a clue about it. There is one bank in Thunder Bay, I must say—and the girl was ever so helpful. Still, there are a lot of people who don't know about that, and that's a really positive outcome for these young adults—if we can save any money and help them when we are gone.

I don't have the answers. I am a single parent, I work full-time, and I'm just speaking on behalf of my son, and also the ones who can't speak.

I snowshoe with young adults who have special needs on Sundays. I love it, but some of them will come with no snow pants—and they have workers or someone that the government has put in there for them. I'll say, "Well, where are your snow pants?" "They're in my closet." Do you know what I mean? The system is kind of broken, and we need to fix this.

Hopefully, I made some sense here.

I know that we do need the funding. I also included my Wesley. My funding has not changed. I've done many appeals since 2005, and now I have no funding till April for my son. That's one of my stories, and I'm sure there are other people who are in the same boat, who are different.

My son would be able to get up here and tell his own story. He wanted to come. He did the closing ceremony speech at the Thunder Bay auditorium for our winter games, so he's good at presenting, but he does not understand as totally as we do. His communication is very different. He can tell you all the stats in hockey and baseball and things like that, and he's very active in the community. I promote that, and I encourage it, and I love him for the way he is.

On behalf of my son, myself and the other people who can't speak for themselves, we need some help and some funding. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for coming to speak to us this morning. I think we all appreciate the fact that you spoke spontaneously. We will get the rest of the information from your written submission, all the data part. So that, I think, was very welcome.

We do have a couple of minutes for each party to comment. Miss Taylor.

Miss Monique Taylor: Thank you, Chair. Good morning. Thank you so much for being here and for sharing your and Thomas's story with us, because it is important that we do hear from you. I'm glad that you made the decision to come and talk about Thomas and just to give us the other information.

You mentioned that you worked in a long-term-care facility, and it's something that we've been hearing quite often, that "we don't believe that young people belong in long-term-care facilities." In your experience, in Thunder Bay, how many young people are you seeing? Do you have an approximate—are there are a lot of young people in your long-term-care facilities?

Ms. Sandi Boyes: No. Actually, I know of one person—and this is one before I became a supervisor; it had to be at least 15 years ago. There was a girl—she was in her twenties. She hated it. She just hated long-term care. She just didn't want to eat. She said, "I don't belong here." I said, "No, you don't." And you know what? She just didn't want to be there. And long-term care, because everyone was older—a lot of them are ready for palliative care. They're there. They're not usually going anywhere else. So it took about three or four years, and

we always spoke about her in the nursing staff. She went to live in a group home. I see this girl now. I don't know if she comes for therapy or why she comes to Heritage—probably for therapy downstairs, because I see a lot of it. She's the happiest person I've ever met.

Miss Monique Taylor: That's wonderful.

Ms. Sandi Boyes: That was the best choice for her: to go into a group home. She would have just deteriorated so much in long-term care.

I know another person—I think he was in his forties—who came to where we were. He had a lot of mental disabilities, whereas people—and he was able to go into the community. I saw him at baseball, and someone had said to me, "Do you know he ate two packages of raw bacon?" I'm thinking, "Oh, no," because this person was a street person, because he didn't have the supports. So I phoned nursing, and I said, "When so-and-so comes back, if he's really sick, this is why." But there was no one to advocate for him. Someone had said they saw him do this at baseball. So how do these people fall through the cracks?

I did phone, and he was okay, but he didn't live for very long. He ended up falling when he was going to ride a bus. From then on, he deteriorated. I don't know if it's being a setting of long-term care, or if it's a mental illness, because in long-term care, we are not equipped to deal with mental illness, and it puts the safety at risk of the other residents and that client themselves. And you'll hear about that in Toronto, in long-term care, and then it goes to everything else—I just went through a big thing yesterday on ethics, too, in long-term care. It was—wow—an eye-opener, too.

The Chair (Mrs. Laura Albanese): Thank you. I believe that Mr. Mauro has some comments to make. Go ahead.

Mr. Bill Mauro: Thank you, Madam Chair, and thank you very much for your presentation, Ms. Boyes. I have just a couple of questions. The first one: Your words for Thomas were that they didn't have a label for him—

Ms. Sandi Boyes: Correct.

Mr. Bill Mauro: —and so there's been difficulty in applying a strict diagnosis definition to his condition.

Ms. Sandi Boyes: Correct.

Mr. Bill Mauro: I've never heard that before, and I'm wondering if, for you, it created any unique challenges in terms of accessing funding for your son, because of that inability to—

Ms. Sandi Boyes: It did, because I would go see one of the doctors here in Thunder Bay, a very well-known doctor, Dr. DeSa. He was for younger children. I said, "Can you give me a label?" And we don't want labels for our kids, when they're children and stuff like that. He said, "NYD." I said, "Well, what's that?" "Not yet diagnosed, and you can have that forever," he said.

But he is intellectual, and even in one of my papers here, they said, "We understand that your child has a very severe intellectual disability." But you know what? I was like, "Yes; I've lived with this my whole life." I don't even know when that letter was, but I thought I had included it.

0950

Those are kind of the weird things that we as parents have to go through through: do a lot of paperwork, and there's not a lot of transparency. That's why I put my things in there. I want my facts to be known, because \$1,800 a year for that is not very much. I don't know if you could do the math—I don't even think that's four hours a week.

I did put some facts in there also about the funding as well. Is my time up?

The Chair (Mrs. Laura Albanese): No, go ahead.

Mr. Bill Mauro: There's still time? Yes, thank you. The other question was, if you could expand for me this bit that you mentioned about the RDSP.

Ms. Sandi Boyes: It's a registered disability savings plan. I think someone probably has better facts than me, but if my son puts in \$500 per year, then the government matches up to I think \$1,500. Automatically, every year, there's \$1,000 put in there if you're investing in this. That's strictly for him after he's 49 years of age.

Mr. Bill Mauro: When did that start, do you know?

Ms. Sandi Boyes: At least—I want to say seven or five years ago.

Mr. Bill Mauro: Five years ago? Okay.

The 49 number—you said that was the—

Ms. Sandi Boyes: The cap.

Mr. Bill Mauro: That's the maximum allowable?

The Chair (Mrs. Laura Albanese): It's the age—49 years of age.

Mr. Bill Mauro: Yes. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones?

Ms. Sylvia Jones: Thank you for your presentation. You made mention of one place, one stop, to figure out what's available and what's out there for Thomas. You're not the first person that has made reference to that. We talked about the transitions and coordination that has to happen within ministries. If you could envision an individual, an advocate, who basically took you from diagnosis or understanding through the various stages—education, health care and ultimately residential options—could you see that being of benefit to you in your journey with Thomas?

Ms. Sandi Boyes: Definitely, definitely, and most parents as well. I shouldn't speak for everyone, but it seems that the only way we find out things is when we know that, "This change is going to come about. What are we going to do? How are we going to figure it out?" Then I'll say, "Did you hear anything? Did you know anything? What are you doing?" So it's parents speaking to other parents in how they're coping with things. But it would have been very beneficial. I never even knew my son was special needs until I sent him to George Jeffrey's when I had to go back to work—I think I went back to work six weeks after I had Thomas—and because he used to fall a lot. The only reason he went to George Jeffrey's was because a good friend of mine's mother-in-law worked there. I didn't want to put my son in daycare. That was my first child. To me, he seemed okay, but he

was later in walking and speaking—we didn't even know if he'd speak.

There are a lot of programs that I went through with that—understanding through George Jeffrey's and the Hanen program and educating myself as best as I could and looking through magazines and talking to people. Some people don't like to approach or they feel really nervous. I'm not the best at approaching but I think, "If I don't do it, how am I going to figure these things out?" So I've tried to be that way most of my life.

Ms. Sylvia Jones: And that type of navigator would be of assistance if you moved locations?

Ms. Sandi Boyes: Definitely.

Ms. Sylvia Jones: If there were changes in your circumstances—you talked about working full-time. The people who are presenting are the strong advocates, but we have to build a system that's going to help everyone with all different levels.

Ms. Sandi Boyes: It depends on what their needs are, how old their son or daughter is, their age group and their ability to do things. We want to have them included, but it also has to be very safe. I had people from an agency tell me they were going to take my son and teach him to ride the bus. Thomas has an awesome memory; he probably knows the whole bus route better than all of us in this room or someone from Thunder Bay. That's not it; it's the safety issue, you know? Going on the bus—if he was normal, I wouldn't even let him go on the bus. Are you kidding me? He talks to everybody. It's a safety thing that these people don't seem to understand. It's more that—and I really don't like saying this—they're book smart, instead of being in our shoes. That's all I can say. I'm not putting them down. I'm sure they're very smart, intelligent people, but they don't feel it in here and they don't live it. So when I'm saying, "I don't want my son to ride the bus," that was totally ignored. I thought, "Okay, you want to spend your day riding the bus with my son? Go ahead." Who am I to say? I'm only his mom. But you know what, you don't want to be on the bad side of these people either, because we're not going to get any money. So we're not in a good place sometimes.

I'm definitely not complaining; I'm just explaining.

The Chair (Mrs. Laura Albanese): Thank you for your openness. It's very much appreciated. It does help us in the work that we need to do. Thank you for being here this morning.

Ms. Sandi Boyes: Okay, and thank you for giving me the opportunity. I'm glad that I did find out about this. I'm sure there are lots of parents who didn't even know about this, as well, in Thunder Bay, because I wouldn't have known if I didn't make the phone call. So thank you.

The Chair (Mrs. Laura Albanese): Thank you.

NISHNAWBE ASKI NATION

The Chair (Mrs. Laura Albanese): I will now call on Nishnawbe Aski Nation to come forward.

Oh, Ms. Wong?

Ms. Soo Wong: Madam Chair, while we're waiting for the next witness, can I ask the researcher to look into additional stuff for the committee? In Ms. Boyes's presentation, in the written submission, she shared with us the goals of her child in terms of securing meaningful employment. My question here—and if the researcher can find information for this committee—is, can we get some data across the province with respect to the Ministry of Education for the students ages 19 to 21 who are still in an existing publicly funded school board, what resources and support they are providing both to the students and the family in terms of transition to the next stage?

Furthermore, I also want to know what kind of collaboration—each of these publicly funded school boards are working with MCSS, because very clearly, Ms. Boyes's concerns raised to us that something happened, because this goal, here, should have travelled from the time when her son was 18, 19, 20, 21 at that school board. If they are a publicly funded school board, I want to know about the collaboration from that district school board, working with MCSS, as the students are going to be transitioned out from that school board. So I want to know about that collaboration and what supports are there for students and the family.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Wong.

We want to welcome the Deputy Grand Chief, and you may begin at any point in time. You have up to 20 minutes for your presentation.

Deputy Grand Chief Goyce Kakegamic: Nishnawbe Aski Nation appreciates the opportunity to speak to the select committee on developmental disabilities. I'm here on the behalf of 49 First Nation communities, not as an individual spokesperson. Our territory runs from the Manitoba border to Quebec and consists of 49 communities: 32 of them are isolated. The only way you can get there is by plane. It covers two thirds of the NAN territory.

My heart goes out to see the report of the urban people, of the challenges as they deal with those in their family who have disabilities. Our First Nations do have that challenge too in our communities. But if you see the need, which should be addressed in urban society, our status situation is worse.

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We take for granted to have physicians. I live in a city. I pay tax; I own a home. I don't even have a doctor. In our communities, there is no physician. There's a nursing station and a nurse. Our children, our youth, adults with developmental disabilities from the Nishnawbe Aski Nation face an alarming lack of services and support. This lack of support is very damaging to individuals with developmental disabilities and their families. All families that are supporting a family member with a developmental disability have a heavy load. But in the Nishnawbe Aski Nation, especially in the remote communities, the stress and the despair are incredible.

The high cost—I suppose you guys came from Ottawa or Toronto. You probably paid only \$300 for a return

trip. In our communities it's cheaper to go from here to Las Vegas than to go and see our medical services from our communities to Thunder Bay. The high cost is enormous. In some cases, this even results in children not being able to attend school, parents not being able to look after their own children, and adults with developmental disabilities getting caught up in the criminal justice system. This is not right. We need to do better. With the right tools and resources, I am sure we can.

The Nishnawbe Aski Nation has the capacity and willingness to work with the provincial government to address these issues in order to provide a better quality of life for all children, but also families living with developmental disability.

Again, I'm here on behalf of our chiefs, our communities. I am their spokesperson. We have the title—in Indian terminology, "Chief" means to be just a spokesperson doing the bidding of who elected you. A literal translation in the native language: You're a spokesperson. So I'm here to say that we are all citizens of Ontario. There are services in urban society; there's none in existence in our communities, and the high cost is enormous.

So it is a challenge, not a problem—a challenge. When we think of it as a challenge, a positive gear kicks in: What can we do for citizens who are part of Ontario, Canada, with developmental disability?

I'll turn it over to my colleague, to my staff.

Mr. Bobby Narcisse: Good morning, ladies and gentlemen. My name is Bobby Narcisse. I'm director of social services for Nishnawbe Aski Nation. I work under the portfolio of Deputy Grand Chief Goyce Kakegamic.

I've been there for close to eight months now. I'm originally from the Aroland First Nation, where I was sitting on council over there and working in social services within our particular communities. I had the great opportunity of working with the deputy grand chief on this portfolio, and I'd just like to briefly touch on some very important points that we've been working on and also different challenges that we wish to overcome with respect to disabilities in the Nishnawbe Aski Nation.

We appreciate this opportunity to speak with you all. We will provide you with a recommendation that is solution-focused. We've heard a lot of the heartfelt stories, and we really identify with many of the challenges faced within this sector, within the province, but the recommendation that we are putting forward to the provincial government is to provide Nishnawbe Aski Nation with adequate resources to conduct a comprehensive review of the current services and supports and the impacts on individuals and their families living with developmental disabilities. The review will provide a basis to develop a comprehensive strategy to ensure families are supported in Nishnawbe Aski Nation.

We would like to acknowledge that all families who are supporting a family member with a developmental disability have a very heavy load, but in the north, especially in our remote First Nation communities, the stress and despair is incredible.

Children, youth and adults with developmental disabilities from NAN territory face an alarming lack of support and services, as the deputy grand chief just said earlier in his opening remarks. It is estimated that the rates of developmental disabilities, learning disabilities and conditions such as fetal alcohol spectrum disorder are much higher in our First Nation communities, especially in the remote north. These disabilities are further exacerbated and complicated due to remoteness, social and health disparities, poverty and lack of services.

The deputy grand chief just also said that it costs more to go to one of our communities than to go to Mexico. It costs a couple grand just to go to our First Nations. With many of our population needing to go to urban centres, such as Thunder Bay or Winnipeg or Sioux Lookout, the amount of resources needed is quite exponential within our territories.

Challenges obtaining a diagnosis of developmental disabilities, including fetal alcohol spectrum disorder, are extremely magnified in our communities. Very few individuals receive disability-related diagnosis. Unfortunately, and only in some cases, these services kick in because of involvement with the justice system, or child welfare. As I'm sure you're aware, this is much too late.

In addition, this places a tremendous strain on the children's welfare system and the justice system. We need to start a little bit earlier. We need to start identifying these disabilities earlier. In our First Nations communities in the remote north, there is a severe lack of services to do so.

The First Nation community-based programs work very hard to address these high needs in their communities, but they're extremely overwhelmed, underfunded and often do not have the infrastructure or the training to carry out the needed support. They are placed in the position of delivering programs in isolation of the clinical supports that are available in other parts of the province and in urban settings.

Developmental support services in the communities are virtually unavailable to clients and their families. Mainstream agencies report that they are able to provide very little compared to what is needed in our remote communities. There are two Community Living agencies that exist on-reserve, and both are in southern Ontario, close to urban settings, whereas there is nothing in our remote communities to help our children and our adults and our youth with developmental disabilities.

Housing supports for adults with developmental disabilities are non-existent. As you know, many of our First Nation communities experience a wide range of challenges, such as poverty, lack of housing and lack of infrastructure. To think, to have somebody with developmental disabilities in our First Nation communities—there's nearly nothing to support them.

There's nowhere to go for specialized care and services on-reserve. First Nation community members frequently are not even referred to services due to the wait times and prohibitive costs. Again, this fact complicates our attempts to advocate for more service.

Many individuals fall through the cracks, and it results in their disability being further complicated, resulting in a poorer quality of life and a higher rate of secondary disabilities. Families experience stress and breakdown because they are not able to care for their child or adult with special needs and have to make choices of giving up their child to care or relocating to an urban setting. Schools are unable to work with many of our children, resulting in children just sitting at home or just left in the classroom, not getting the supports that they need.

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Elderly parents caring for adult children with disabilities are under great stress, often dealing with adult children who are self-harming and behaviour that places the parents at physical risk. Elderly parents have to face the very difficult decision to not care for their adult child, resulting in the person with disabilities being turned over to the hospital, living in a long-term-care facility or becoming homeless, living on the street. In many cases, people have started to believe that it is not possible to get help in our First Nation remote communities. The result is lost opportunities for early intervention, and lifelong complications.

Other challenges in our area include jurisdictional issues that create serious problems for people to access service. I'll give you one example: The mechanism to cover travel costs for First Nations accessing health services is the federally funded Non-Insured Health Benefits Program. Non-Insured Health Benefits will only approve travel costs for an OHIP service.

Most assessment, developmental or rehabilitation services are not available in the hospitals that serve the NAN communities. These services are provided through the Ministry of Community and Social Services or the Ministry of Children and Youth Services' funded programs. This obstacle impedes the access to many services. Jurisdictional issues are very evident in our communities.

Many other barriers exist that result in people not accessing mainstream services. This situation has become so protracted that First Nations community members frequently are not referred to services due to the prohibitive costs of travel and the significant wait times.

Education: Here is another big barrier, and also obstacle, that we have. High-cost special education is a major issue that impacts the programs and services of students in the Nishnawbe Aski Nation on an ongoing basis. There are many instances where the identification rates range from 20% to 40% of the student population that require high-cost special education. There's no guarantee that there is funding to undertake high-cost special education assessments and that, if the assessment is undertaken, there is funding to ensure that the required services are in place.

Under the federal government's High-Cost Special Education Program, the funding is not based on need but rather on the distribution of available funds through an approved formula process. There is simply not enough funding to meet the needs of students, whether it's

through formal identification or teacher-based assessment and delivery of intervention strategies. We continue to participate in the Ontario First Nations Special Education Working Group to advocate for the needs of our students.

With respect to service providers, based on the experiences of organizations providing services in Nishnawbe Aski Nation territory, they have outlined the following key issues as predominant:

- individuals are often misdiagnosed, victimized or bullied;

- people with developmental disabilities live in isolation, with nothing to do;

- no respite services for families in remote communities of the Nishnawbe Aski Nation;

- clients served in First Nations communities are more likely than other northern clients to suffer from physical and mental abuse or to have attempted suicide—as you know, the suicide rates in our First Nations communities are very high. We see it in the media. With respect to many of our students, especially coming from their home communities and their parents to go to school in urban centres, it's quite a challenge; and

- many referrals from First Nations communities are complex, needing inter-ministerial intervention.

Ladies and gentlemen, in conclusion, the essential barriers to supports and services for people with developmental disabilities in Nishnawbe Aski Nation territory seem to be identification and diagnosis; adequate resources for both mainstream agencies and community-based services; a culturally relevant system linking support back to the community; and logistical and jurisdictional barriers.

Unfortunately, there is very limited information and data on the incidence of developmental disabilities in Nishnawbe Aski territory. This leads to gaps in identifying the number of people requiring services and support, and a poor overall systemic response.

The people in Nishnawbe Aski Nation territory are struggling in many areas: health, social, education, economic and housing. The general conditions of the communities, layered with an estimated higher rate of complicated disabilities, mean the most vulnerable people and their families are placed in unacceptable conditions. This needs to be addressed.

Again, the recommendation we are putting forward is for the provincial government to provide the Nishnawbe Aski Nation with adequate resources to conduct a review of current services and supports, and the development of a comprehensive strategy that will support individuals and their families living with developmental disabilities.

Further, the increased participation and co-operation of various ministries working to this end is also required—communication and co-operation, and also the inclusion of First Nations input as to finding the strategies with respect to this area.

With all the changes going through our province with respect to resource development and the Ring of Fire and many of the resources that are being accessed in our traditional territories, I think it is imperative that—First

Nations want to be a part of that. We want to get our citizens involved in that process as well. As treaty partners, we ask that the government also invest in our people. There are many challenges that are facing our First Nations communities in the remote north, and I think it's worth an investment in our region, within our families as well, to partake in this initiative.

I think I'm almost out of time, but I really thank you for having us and listening to our concerns. We look forward to working with you to come up with a mutually beneficial solution in this area of developmental disabilities.

The Chair (Mrs. Laura Albanese): We want to thank you for coming before our committee, and we want to thank the Deputy Grand Chief for being here as well, for helping us to shed some light on the challenges that you are facing in the community, and for giving us these very valuable suggestions. Unfortunately, as you pointed out, we are out of time, and I will have to move on to the next presenter. On behalf of all the committee members, thank you very much once again.

Mr. Bobby Narcisse: We'll be emailing you our information as well, so if you have any questions or comments, you can also contact us from there. Thank you very much.

The Chair (Mrs. Laura Albanese): That will be most welcome. Thank you.

Ms. Elliott?

Mrs. Christine Elliott: Madam Chair, while we are waiting for the next presenter to come forward, I'm wondering if we could get some information on the federal travel grant situation and the educational grants so that we can have a better understanding of what's funded and what's not funded.

The Chair (Mrs. Laura Albanese): Yes.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): That would be welcome.

Ms. Wong?

Ms. Soo Wong: Madam Chair, while we're waiting for the next witness to come forward, can we get more data on the new medical school up here and the relationship and support provided to these remote communities—because that was one of the goals for this new medical school: to address some of these rural communities. So if we can get some data and information, that would be really helpful.

The Chair (Mrs. Laura Albanese): That would be from training, colleges and universities?

Ms. Soo Wong: No, it would be MOH, Ministry of Health and Long-Term Care.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzi Hunter: Yesterday we heard about identification being done through a community partnership, I believe, with Surrey Place. But in terms of diagnoses and services for individuals and families coping with developmental disabilities, are there currently any supports in place for this territory? Can we ask the ministry?

The Chair (Mrs. Laura Albanese): Is that fine? Thank you.

1020

COMMUNITY LIVING THUNDER BAY

The Chair (Mrs. Laura Albanese): Now we will welcome Community Living Thunder Bay. Please state your name and your title before you begin. You'll have up to 20 minutes for your presentation.

Ms. Lisa Louttit: Thank you. Good morning. My name is Lisa Louttit, and I am the executive director at Community Living Thunder Bay. With me is Jordan Pretchuk. He is a member of Community Living Thunder Bay's council and also a member of Community Living Ontario's council.

Jordan and I would like to thank the committee members for this opportunity to address the committee and share concerns on behalf of Community Living Thunder Bay this morning. We'd like to start off by lending our support to the presentation made by Community Living Ontario, which I'm sure you heard about. As a member of the federation, we are pleased with the concerns and recommendations that Community Living Ontario has put forward. But specifically, today, Community Living Thunder Bay would like to emphasize a couple of areas in which we believe some immediate change is needed.

The first is around inclusive education at an elementary, secondary and post-secondary level. If we are to be serious about people who experience disabilities attaining real jobs and contributing to community, there needs to be a real and shared vision around inclusive education in our province. Elementary, secondary and post-secondary education prepares students to enter the world as contributing members of society. There have been some great steps taken toward inclusion through policies such as regulation 181/98, which states that a regular classroom should be the first option as a placement for all students, but progress remains scattered and inconsistent across the province. The reality is that many students across the province are not fully included in typical classrooms. Many students are stuck in segregated classrooms and are not accessing the quality education they need to prepare them for the world of work and contribution to community.

Sadly, this reality continues often into post-secondary education as well. Opportunities for inclusive post-secondary education in Ontario are very limited. There are a number of colleges that currently offer opportunities through CICE programs, but there are not enough. Fortunately, there are some great resources that we can draw on that can assist the province in making the changes needed to right this situation.

I did bring a resource along. It's called *A Promising Path to an Inclusive Life*, which chronicles over 20 years of experience around post-secondary inclusive education opportunities for adults in the province of Alberta. A number of universities and colleges in Alberta offer opportunities where students can participate in classes

and programs of their interest, as well as participate in campus life. These opportunities are made possible through voluntary peer mentoring by non-disabled students and funding for facilitators that work with the students, the peer mentors and the professors to ensure that students are accommodated in the classroom and are participating as fully as they can in the course. Many of these students have been able to go on and get real jobs in their community due to this experience. In addition to enhanced employment opportunities, these students have also had the pleasure of building friendships and relationships within their networks of supports that are lasting. It is our hope that this can happen in Ontario for adults who experience disabilities.

Another positive example of leadership in the area of inclusive education is the state of Vermont. Vermont has been providing inclusive education for students at an elementary and secondary level for over 30 years. In 1987, the State Board of Education developed a document entitled *Vermont Education Goals* that articulated the restructuring of schools to support the high performance of every student, and no vision of special education as we know it, creating funding formulas that allowed resources for special services in the classroom—typical classrooms—with the student. It is essential that Ontario's education systems implement the changes needed to make full inclusion in typical classrooms with effective supports a reality.

Quality education at all levels that focuses on the students' gifts and capacities will open doors for students that experience disabilities and will ensure greater success in employment. It will also have a profound effect on organizations such as ours, Community Living Thunder Bay, as young adults growing up accustomed to fully inclusive experiences throughout their school years will demand more individualized and responsive services for living and employment and community participation. Young adults and their families will no longer be satisfied with the traditional congregated supports that many organizations still offer.

The other area that we'd like to touch on is the need for flexibility and creativity, for organizations to shift away from traditional support models. There are many associations, such as Community Living Thunder Bay, that still provide traditional congregated services such as group living, sheltered workshops and day services. Although these supports may make sense for some people, we're finding younger people coming into our service don't want these types of supports. Many people that we serve and that currently receive these types of supports want a better quality of life and want to explore other options.

Many organizations, like Community Living Thunder Bay, have a desire to move toward providing individualized supports that promote inclusion and self-determination for the people we serve. However, we need flexibility and the resources to move forward and make the needed changes in service delivery for people.

It's often challenging for organizations to maintain current supports while trying to unbundle resources and

provide new and innovative supports for people who want to try other things. Allowing for more flexibility in meeting service targets and control over vacancy management, even on a time-limited basis, will in the long run allow organizations to increase service capacity for people currently receiving services, improve quality of life, and create capacity for people on the wait-list. Short-term funding to maintain existing services while new and innovative options are explored will help organizations to make these transitions.

Resources for training around initiatives such as positive approaches, and connecting with organizations that have already successfully shifted away from traditional services and that are willing to share their stories and experiences, can enhance leadership within organizations and build confidence in organizations that want to make these changes.

We also need some flexibility and interpretation around compliance standards as well. It's our belief that the standards set in the quality assurance measures are well intended and are to set a foundation for minimum standards and safeguards around service delivery. The challenge is that some of these standards do not make sense, nor do they ensure a minimum standard.

An example of this would be the requirement for organizations to provide protection skills training to all direct staff. This is a huge waste of resources that could be better used for training around positive approaches, communication skills and many other areas of training that staff need within organizations. Many of the people we serve pose no threat to staff, and there is no need for protection skills training. Not only that, but there's lots of research to support that using restraints on people only further traumatizes people. We would like you to allow organizations the flexibility to determine the type and scope of training needed to ensure that people that we serve, who might engage in challenging behaviour, are supported more holistically, and that we can keep our staff safe.

Jordan would like to share his experience in finding work in our community.

Mr. Jordan Pretchuk: My mom became a member at the first self-advocate meeting she attended here. Parents expressed their concerns to Lisa, as director—and her skill and dedication to serve this very full position.

Mom, as a parent, found information necessary for help was by word of mouth, and through other parents. They were in the same position as her. Outside of these parents, information seemed little to non-existent.

Her first lead was Lutheran Community Care, which had me tested at Options. Through Lutheran Community Care, I was sent to the ministry director, to the March of Dimes, for job training.

After my job training, I was informed by word of mouth to go to Monty Parks, but there was a long wait-list of names I would be placed on. After my job training, I remained at the March of Dimes to join the activities out there. In the meantime, I tried to get employment, to no avail. It was suggested to go back to Lutheran Com-

munity Care, and they tested me again and put me on the list with Monty Parks. I gained a job through the March of Dimes through money funded. It opened the door for me to be on the March of Dimes work team.

As it happened, I was encountered by Marie Morrison, my worker at Monty Parks, to help me in a job search. Through Marie, I made connection with the activities of Monty Parks and the self-advocate group.

Directing me, Pat Tront and Morgan Austen have been most helpful in managing and directing me in self-advocacy group. I am very happy to receive this opportunity to help extend myself to community life and activities that have benefits for my special needs, living and working in the community.

1030

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Lisa Louttit: Thank you very much.

The Chair (Mrs. Laura Albanese): Well, thank you for being here this morning and for presenting to us. We do have some time left for questioning. I believe it is the government's turn to start this time. Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much for being here today and for sharing with us the ideas that you have from your years of experience on how to improve and strengthen the system.

I also particularly want to thank Jordan for sharing your experience with living and working in the community. It seems like it's a positive one for you, and I think that's the best outcome that we can seek.

You made a comment that having more control over vacancy management would be something that would be advantageous for you. Can you maybe talk a little bit about how you see that and why?

Ms. Lisa Louttit: Having more control over the vacancy management?

Ms. Mitzie Hunter: Yes.

Ms. Lisa Louttit: Okay. It's not that we don't agree that there should be vacancy management and a transparent system; it's that sometimes—if I could maybe walk through an example, that might be helpful. For instance, if we have a number of people that live in a particular home—say four people in a group home—that want to try an alternative living option, the challenge is that one or two of those people might want to move out temporarily and try this option, and it takes time to make sure that it works for them. It could be a family home or a shared living arrangement or it could be a more independent SIL-type option. It takes a long time sometimes for people to know that that's going to work for them, so we're not in a position to be able to declare a vacancy right away. We need a little bit of time to make sure that that situation is going to work with that person. It's not always easy, either—if there is a vacancy, sometimes it will give us an opportunity to look at that particular living situation, that group home or that location, and maybe create more movement for people to explore different options, but then we have the burden of the service target. There are just a lot of barriers in the way that prevent us from being able to be more flexible in moving

our resources around while still trying to maintain the core services while people want to experience other things. I don't know if that makes any sense or not.

Ms. Mitzie Hunter: I think it's very helpful, because we also have a waiting list that we've heard about as well.

Ms. Lisa Louttit: Yes, and we're very mindful of the waiting list and the pressures that are out there, but if we can have more flexibility to look at what we have and at where people want to go in terms of the people we're currently supporting, we're pretty confident we can free up more resources in the system to address the wait-list down the road. It's just that we need that time and sometimes we need the flexibility around our service targets and maybe a little more enhanced funding sometimes on a short-term basis until we can create those opportunities for people to try different things. Then we believe it can free more money up in the system, longer term.

Ms. Mitzie Hunter: Okay. Is there time for one more?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Mitzie Hunter: Okay. You also talked about needing flexibility around the job training and having more choice based on the needs of your employees and the client group that you're serving. Can you talk a little bit about health and safety and how those standards are maintained throughout your facilities?

Ms. Lisa Louttit: The health and safety—

Ms. Mitzie Hunter: For employees.

Ms. Lisa Louttit: For employees. I referred to the protection skills training. Is that what you mean?

Ms. Mitzie Hunter: Yes.

Ms. Lisa Louttit: Okay. For instance, one of the pieces of the quality assurance measures requires us to train all of our direct support staff with one of three approved providers that do training around protection skills for staff. So that's a lot of money and, depending on the system that you use, you may be required to do that mandatory training with all your employees once a year.

Not everybody needs that. For instance, our organization wants to take a zero restraint approach. We don't want to use restraints. We believe that using restraints further harms people and causes them trauma. A lot of the people we support experience anxiety. There are lots of reasons why it doesn't make sense to use physical restraints on people. If we say, as an organization, that we are only going to use protection skills training or we want to try other approaches such as positive approaches, we will be in a non-compliant position with the current legislation, the way it's structured.

What we're asking for is to allow us to use some best practices, use more holistic ideas around supporting people who engage in difficult behaviours. Let us decide what staff and how many staff we need to train, and how often, and what methods we need to train them in so we can save money, and that money can go for training

around more meaningful things that can help the people we support and keep our staff safe.

The Chair (Mrs. Laura Albanese): Ms. Elliott.

Mrs. Christine Elliott: First of all, I'd like to thank you, Jordan, very much for being here today. This is what this committee is all about. The extent to which we can hear from people like yourselves with lived experience really helps us, in a very deep way, to understand what we need to do to continue to support you and allow as many opportunities as possible for you. So I really appreciate you being here.

Lisa, I have a few questions for you. First of all, can you tell me how many people you serve here in Thunder Bay?

Ms. Lisa Louttit: Community Living Thunder Bay serves around 300 people. I'm relatively new to my role, so I'm learning some of these statistics myself; sorry.

Mrs. Christine Elliott: Okay. We do have some information on education, particularly post-secondary education. I have some familiarity with the CICE program, and it is wonderful. First of all, it's offered at your local college, I'm assuming? Can you tell me how many students they take per year? Also, what is the job experience for those graduates, and how many are able to find employment?

Ms. Lisa Louttit: I'm actually still learning about the community of Thunder Bay. I just moved here. I am from Sault Ste. Marie, and we do have a CICE program in the Soo. I worked at Community Living Algoma, so I was very familiar with the CICE program there. I know a lot of the people we served attended that program and were able to get jobs.

I think the CICE program is an excellent example of inclusive post-secondary education, but I really would love the committee to turn their attention toward the work that is being done in Alberta. The beauty of the work that's being done in Alberta around post-secondary inclusive education is that it is not based on pay support; there are some resources that are focused on having a facilitator present on the university or the college campus, who coordinates things. To me, the real beauty of that program is that it's based on voluntary peer mentoring with students who don't experience a disability. It's a very natural connection, and they create, in some cases, lasting friendships. Although it's probably not a certificate program—some of the CICE programs offer a certificate at the end. The students who attend the universities and colleges in Alberta—there's no certificate; it's more like auditing a program. The benefit is that they're fully included in the course. It's accommodated at the level they need to be at, and they're experiencing and studying things that they're really passionate about that typically aren't available to people who experience disabilities. There are people enrolled in music, arts, psychology, literature and all kinds of courses that you and I might be interested in.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Sorry, the time has already transferred into Ms. DiNovo's time.

Ms. Cheri DiNovo: Thank you, Jordan. You gave a wonderful presentation. Thank you very much for being here. It's important that you're here.

Lisa, I have some questions for you. One of the ongoing issues that we're trying to get our heads wrapped around in this committee is the wait-list numbers. We've had some numbers come forth from the ministry, ComSoc, but they're very, very at odds with the numbers we're hearing, for example, from Community Living. I'm really asking you to help our researcher out a bit here, for Community Living Ontario, if you have a sense of the number of people on wait-lists for your services across Ontario. Is there an idea? Because you've had experience with Community Living Ontario as well.

1040

Ms. Lisa Louttit: I'm not going to be able to quote you statistics today, but I know that we can get that information for you.

Ms. Cheri DiNovo: Yes, could you, because—

Ms. Lisa Louttit: Through email, absolutely.

Ms. Cheri DiNovo: That would be extremely useful. The other thing is, in terms of inclusive education—and we hear from you and have heard from the others. We also earlier heard somebody come forward as a witness who was touting her experience of, in a sense, exclusive education, which is a special-needs school that's set up. I'm wondering if you could comment on that because we've heard on this committee that there's no one solution for all. We really need to look at this as an individualized program. Could you comment maybe on your experience or your clients' experience with exclusive special-needs education or schools set up specifically for that?

Ms. Lisa Louttit: I think sometimes that what families really want is they want to make sure that their child is safe when they attend school and that they're not experiencing bullying. I certainly am not a parent and I can't speak for parents, but I think sometimes parents maybe default to segregated schooling or segregated classrooms because their hope is that their child will be safe from bullying and the kind of treatment that can go on. So I understand sometimes the desire for a segregated classroom or a school. But I think there is tremendous research to show the benefits of being able to go to school with your typical peers and classmates. It's not only the benefit to the child with the disability, but it's also the benefit to the children without the disability and to the whole social network of that school.

Those kids later go on into society and expect that people who experience disabilities will be fully included in society. Those students go on to own businesses and create employment opportunities and naturally assume that people who experience disabilities do have gifts and interests and passions to offer society. I really believe that inclusive education, if it can be something that can be required—typical classrooms, regular classrooms, no segregated classrooms—has the power to change how we do business as organizations. I think the more inclusive people are and the better the education they get and the

more our society understands the gifts and what people who experience disabilities have to offer—we will be compelled as organizations to offer individualized, creative and innovative supports that make sense for people, but at the same time address the concerns families have around needed resources. We'll be able to free up a lot of money in the system to support people the way they want to be supported.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation this morning and for your valuable suggestions.

RYERSON UNIVERSITY: REIMAGINING PARENTING

The Chair (Mrs. Laura Albanese): And now we'll call on Ryerson University, Reimagining Parenting, to come forward. As you're making your way up, I will remind you that you have up to 20 minutes for your presentation, and if you use less than 20 minutes, then we will have some time for comments and questions. If not, we're just very happy to hear from you and hear your comments and your input. If you could begin by stating your name, that would be wonderful. You may begin any time you feel comfortable.

Ms. Pat Seed: First of all, we'd like to thank the Select Committee on Developmental Services for allowing us the opportunity to present today. My name is Pat Seed, and I think I'll let Cher McCullough Monteleone introduce herself first.

Ms. Cher McCullough Monteleone: Hi, everyone. My name is Cher Monteleone. I'm married and a mother of two young children. I'm also a woman with a disability and a self-advocate and co-researcher for the Thunder Bay Reimagining Parenting project.

Ms. Pat Seed: Now, Reimagining Parenting possibilities is a very important project to me. My name is Pat Seed. I've been a volunteer in this community since 1980. I'm currently on many advisory boards and so forth for people with disabilities. I'm currently president of CWDO, which is Citizens With Disabilities—Ontario, which is an Ontario-wide organization of people with disabilities devoted to people with disabilities and things like the AODA. We're very much involved in public education and in watching the Accessibility for Ontarians with Disabilities Act to make sure that it gives all of the standards force so that they can be put into effect.

We also give input to the Council of Canadians with Disabilities. They are a Canada-wide organization. Both of us, actually, give information and input into the United Nations convention for the rights and so forth of people with disabilities.

Now, I learned about this presentation during the weekend of January 4 and 5. I had written a letter to our MPP, Michael Gravelle, and he called me, actually, at home and he was very interested in this project that you will see outlined in the handout that you will look at. There were three members of the group that were coming up last Monday, on January 6, and they came up from

Toronto. One of them was Esther Ignagni. You have her name there today. She's from Ryerson University. Melanie Moore came up here. She's from the Centre for Independent Living in Toronto. Also, Renee Morin, who is a self-advocate.

Michael wanted to meet with us about the project. We wanted to describe some of the information that we had. He also wanted to provide us the information on this committee. So we met at the Hagi building at 1201 Jasper Drive. Over persians and pizza, we discussed it for about an hour and had a very good meeting. Today we'll give you some of the information. I know that you've received a lot of information so far. You have also had a lot of historical information, so I'm going to scan over a lot of that, and give you specifics about the Reimagining Parenting project.

It's a collaboration of research which has the following organizations participating in it: Ryerson University is one of them, and I mentioned Esther Ignagni, who is the principal investigator; McMaster University is also part of it; Western University; Strength-Based Parenting Initiative, which is SPIN, and that involves Melanie Moore, who also is with the Centre for Independent Living. Actually, Esther and myself are also on that Strength-Based Parenting Initiative. As I said, I'm with the Citizens With Disabilities—Ontario and also involved with Springtide Resources.

The members of the collaborating committee really worked together. They've been working together for a little over a year now on this whole parenting project, and it has been really eye-opening and a learning experience for all of us. There are various sites in Ontario. There is one in southern Ontario; there's one in northern Ontario, which we are part of in Thunder Bay; there's eastern Ontario; central Ontario; and also there is a group in Ottawa who are parents of aboriginal culture, and they have developmental disabilities. They're taking part in the project as well.

1050

The additional members of the group are self-advocates. There's about six of them in the Toronto group, as a matter of fact. I'm the site investigator for Thunder Bay, and Cher is one of our investigators, co-researchers and so forth, in Thunder Bay.

The Reimagining Parenting project—you know that it's a human right for people to be parents, and you've heard a lot of talk about the United Nations and so on and so forth. We like to build up the enjoyment of relationships and family life for people.

It's very important for the parenting project and SPIN to be able to public-educate and to do all those kinds of things that will help people understand more and help people get more information. We want people to be able to ask questions. We want people to be able to participate in the project.

To that end, we have people with developmental disabilities and intellectual disabilities who actually are part of the project. They're doing the interviewing. We team up with them, and it works out really, really well.

We're gathering stories across Ontario about parenting experiences, and we really know that this is going to enhance everyone's lives.

The long-term goal of the project is to develop materials for those who create policies, those who create educational materials and so on and so forth, so that they can be able to have the information they need and they'll know what more people need in addition to what you've heard today.

The project grew out of the work of the SPIN organization, as I said. SPIN is definitely an Ontario-wide organization.

What I'd like to do is go to the recommendations, because I really think that you have heard a great deal about the history and so forth. I'll give Cher a chance to find her page and I will have her explain to you the first six recommendations that we have.

Ms. Cher McCullough Monteleone: Our recommendations:

- Include, in a meaningful way, the voices of people with developmental disabilities in policy and program development and implementation in matters that affect them and their families.

- Ensure that all parenting, sexuality, relationships and reproductive health resources are developed and accessible to people with developmental disabilities and that these comply with the AODA—Accessibility for Ontarians with Disabilities Act—standards.

- ODSP rates must be at an amount that is enough to support dignified family life.

- Social and supported housing for people with developmental disabilities needs to be designed to support families led by those with developmental disabilities.

- Ontario child welfare agencies should receive training and education about developmental disabilities and should work together with developmental services to make sure that parents have adequate and appropriate supports.

- Developmental services, disability services and child welfare agencies should work with people with developmental disabilities to create and facilitate alternative parenting arrangements, including co-parenting, open adoption and family configurations that continue relationships between biological parents with developmental disabilities and their children and grandchildren.

Ms. Pat Seed: If you think about it, many people do not know people with developmental disabilities who are parents. So, to that end, we really feel that there needs to be also education for the general public and everyone, including politicians and all kinds of policy-makers and so on and so forth, to be able to have them know about developmental disabilities and intellectual disabilities.

We are all familiar with the term “handicapped accessible,” by the way, and we know that that means wheelchairs, ramps etc., etc. Well, the opportunity for us is right now, to show that we are very serious about accessibility for those with developmental disabilities. That's really why I thank you, as a committee, for coming today

and taking all the information that we have and, in fact, going across Ontario for these presentations.

You might also think of accessibility in other ways after this group of presentations. Very often, situations with people who are blind or visually impaired, and also situations with people who are deaf, hard of hearing or profoundly deaf are not addressed as far as accessibility. Again, I say that you really see most the people—the accessibility—with wheelchairs, ramps and so on and so forth, and I think a lot of eyes need to be opened.

I will allow you to read this presentation at your leisure, and I definitely can be contacted for questions. I also have more copies of the presentation, should there not be enough for media or for the public who want them.

Now I'll take your questions.

The Chair (Mrs. Laura Albanese): Well, thank you. Thank you for coming today and for your presentation. We don't have a lot of time for comments and questions, but I will turn it over to Ms. Elliott to start with.

Mrs. Christine Elliott: Thank you very much for being here today, Pat and Cher. You have really opened our eyes, as you said you wanted to do, to some of the issues around people with a developmental disability who are parents and have families.

I'm wondering, Cher—if you don't mind if we ask you a few questions, as much as you feel comfortable with—if you could tell us about any of the problems that you and your family had in terms of, say, for example, finding housing. Was that a difficult thing for you to do?

Ms. Cher McCullough Monteleone: Not really, because we had already found a place before we had the kids.

Mrs. Christine Elliott: Okay, so that wasn't a particular issue for you. I'm looking at some of the recommendations that you've made, and you've indicated that that's sometimes a problem and it's something that we need to look at.

Did you have any problems with any child welfare agencies, or with any organization, for that matter, with respect to parenting, specifically?

Ms. Cher McCullough Monteleone: I did when my first child was born. CAS was involved for a little bit, but they found no issues so they got uninvolved. But, yes, other than that—

Mrs. Christine Elliott: Okay. So they've pretty much left you alone to be a parent on your own.

Ms. Cher McCullough Monteleone: Yes.

Mrs. Christine Elliott: Okay. That's very good. Thank you very much for sharing that with us.

The Chair (Mrs. Laura Albanese): Thank you. Miss Taylor?

Miss Monique Taylor: Hi. Good morning. Thank you so much, Pat and Cher, for being here with us today and for bringing a different piece of the puzzle to the table.

Yes, one of the things that I was wondering about before I actually got to the recommendations was how the child welfare system was involved. Was it intrusive?

Was it helpful? What are the experiences that families are facing when it comes to having children?

Ms. Pat Seed: Very often, the children are taken away from the families, and that is done, so to speak, as a protective measure, instead of working with the families to be able to raise their own children and to be able to have the supports to do that.

I've seen Cher very much involved with her two little children. She has a little girl who's eight months and she has a little boy who's—four?

Ms. Cher McCullough Monteleone: Three.

Ms. Pat Seed: Three. She gives them boundaries; she gives them all those kinds of discipline things.

1100

Only by education is it going to be that people would be able to know—and this includes sexual education, information on marriage, information on parenting, information on child rearing and so on and so forth—child development etc. All of that is needed.

Miss Monique Taylor: It's fabulous—

The Chair (Mrs. Laura Albanese): Thank you. Sorry, Miss Taylor. I have to move to Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair. I want to thank you both for joining us here today and bringing your part of this forward, because it's a perspective that we need to consider.

Your first recommendation is to include, in a meaningful way, the voices of people with developmental disabilities in policy and program development and implementation, and I think that's a very important consideration—and as a committee, there have been many different ways that that is being done, and I think your contribution is helping to further that.

I also noted that the network of support around this project seems quite extensive, through the universities and through community-based programming. I really look forward to seeing the results of your work. Much of what you're attempting to do is to change attitudes and behaviours, and that will influence support policy and then the supports that are required.

I just want to say congratulations on your work, and I look forward to seeing more of it as it unfolds.

Ms. Pat Seed: We really appreciate your time, and we really appreciate the fact that Michael Gravelle took it upon himself, on his own time, to come over to us and meet with us. He was very interested in the project.

The Chair (Mrs. Laura Albanese): We will let him know. Thank you very much once again for presenting to our committee and bringing this different voice and different perspective to the table.

Ms. Pat Seed: By the way, if you need a phone number for contacting me, you can use 807-473-0909.

The Chair (Mrs. Laura Albanese): Thank you very much.

MS. DEBRA JOHNSEN

The Chair (Mrs. Laura Albanese): We'll get ready now for our next presenter, Ms. Debra Johnsen.

I see that you're getting ready for a video that you have for us.

Ms. Debra Johnsen: Yes. My name is Debra Johnsen. It's a pleasure to be here. This is my friend Tara Lennox.

The Chair (Mrs. Laura Albanese): Good morning.

Ms. Debra Johnsen: My son, Lindsey, is just sitting in the front row. He's comfortable where he is, so he'll just listen.

We've circulated the CD. I'm going to make sure there's no sound on it. When you're flying back to Toronto, you'll be able to put this in your laptops and listen to the terrific music, listen to the lyrics. It's a wonderful—

Interjection.

Ms. Debra Johnsen: We'll get you one, Tara. She wants the chocolate that's attached to it.

Welcome to Thunder Bay. You've brought some warm weather. I thank you for this opportunity. Good morning.

My name is Debra Johnsen. Firstly, I am a mom, one of many that you will likely be hearing from. Thirty-two years of learning much from my son, Lindsey—he has never spoken a word but has touched many lives.

When I chose to present, it was based on one of those personal experiences that I know are shared by many across not only this province but the country, and, I believe, like many of the challenges we collectively are facing, could quite easily be resolved.

I applaud this government's vision in seeing the urgent need for a comprehensive developmental services strategy.

A communication that I've circulated to the members here, coming from Ted McMeekin, Minister of MCSS, was quite shocking to me. It speaks of funding, and as a parent I was quite appalled by the numbers. When I read in this communication that there was \$42.5 million a year added to developmental services to help 1,000 adults and their families with new or additional supports and that there is \$620 million in new annual funding since 2003, a 63% increase, I want to say, "Where is it hitting the street?" We're not seeing it as individuals and families. The system is broken. These facts are impossible to grasp, knowing first-hand that there are few examples of where it is having successful effect. The stories you are hearing are testament to a complex system that needs to be unwound in many ways but that, in my opinion, starts at the community level.

As a family supporting our 32-year-old son, Lindsey, we have been extremely active in advocating for independent planning and facilitation, individualized funding, and allocation mechanisms that ensure access, fairness and equity. Lindsey has been extremely fortunate to be living with two other fellows who over the past 10 years have become family. One of them is Michael Gravelle's brother. We're very, very blessed. Mark Gravelle has become one of Lindsey's other brothers.

We are part of traditional services offered by Community Living, the dreaded group home that you're

hearing about. Sure, there have been challenges, but the bottom line is that Lindsey is in a loving and caring environment. He has a network of family around him that advocate and push and prod the system to be more inclusive and responsive to his needs.

My current most pressing issue is Lindsey's health. Over the past year, he has lost more than 30 pounds—I can only wish that would happen—likely due to dental hygiene issues. Many of the persons who require the specialized services of day surgery for simple dental cleanings know first-hand that of which I speak. The stories are horrific, the wait-list four years and longer.

I spoke with a mom a few years ago whose daughter was diabetic and couldn't eat and couldn't get time for an abscessed tooth. Our wonderful dentist, who is well known as an ardent advocate, has been hard-pressed to find solutions. He has told of having to stop a cleaning halfway through because he ran out of ODSP funding. I guess, similar to our group plans, there are limited units offered, and they're not cumulative from year to year—in my mind, a possible simple solution—despite waiting four years to get into that much-coveted OR space at Thunder Bay Regional. Can you imagine getting half of your teeth cleaned? Any of us would be outraged. Another issue, according to this dentist, is lack of OHIP coverage for the necessary anesthetic. This is unacceptable.

As parents, we've advocated, we've gone to Thunder Bay Regional hospital, we've talked to the head of that department, but still lots of discussion with no resolution. So here I am, a mom worried sick about a child whose weight loss is striking and very likely due to mal-absorption issues related to gum disease. We are on this wait-list to have all of his remaining teeth excised in the hopes that some of the wasting will abate. This is a guy who loves to eat, loves food, loves car rides, otherwise loves life. There are so many times that we wonder how much of his self-abusive behaviour might be related to a toothache. Once again, imagine yourself in this scenario.

I bring this forward hopefully to address some huge shortcomings. I've included a Globe and Mail article that was in a recent paper. The Canadian Dental Association's Peter Doig admits that people with special needs have limited access to dental care. He says that oral health has never been made a priority, and that "One of the problems is that it comes down to an issue of funding." There's that dirty word once again: "funding."

1110

So what are my recommendations to you? It's totally unrelated to dental care, but it fits, and I think it will resonate with you. Provide supports in a proactive manner. This will reduce the costs of having to provide supports in times of crisis. From my perspective, investing in circles of support or networks and nurturing their development through the early school years and beyond are key to transformation.

In my humble opinion, the failure of the Choices project in Thunder Bay was this missing link. Even though the development of networks was a critical piece

to the Choices project, which was that individual funding model, it was not seen as pivotal once that pilot project was finished.

I was part of a family-led advisory committee that pushed really hard. We tried really hard to say that this was a pivotal part, but unfortunately that vision got lost. It was consumed by the system, and the Lutheran Community Care Centre became another service provider. Creativity and innovation were thwarted by old thinking.

Loving relationships are key to well-being. Without social supports, health care suffers, choices diminish, vulnerability increases and there is a risk of being caught in an impersonal service delivery system. Whether we're developmentally challenged, whether we're quasi-normal or we're seniors, that is a truth.

Secondly, I'll call it the three Is: independent planning and facilitation, individualized funding, and innovation. Families have been underground for years. They continue to be jaded on many levels, without much to encourage their entry into this vortex. The funding facts articulated by Minister McMeekin should outrage all of those families supporting individuals.

Individualized planning, facilitation and funding, coupled with a vibrant network of support—as I suggested early on—at the grade-school level, would allow for a shift in power and control, where it should be: in the hands of the individual. Unbundling of existing services is necessary so that everyone receiving traditional services is aware of what fundings are allocated. This will lead to and will encourage accountability, innovation and creativity.

To have all employment in this sector tied directly to outcomes—how is your job producing a positive experience for that individual supported? I know, wishful thinking. Yet families are being told of a freeze to their support dollars and to be more creative, and we wonder why families are underground?

Lastly, creativity and innovation are the master key to managing fiscal realities. In order for this seed to be nurtured, there needs to be a breaking-down of barriers and silos. There needs to be a demonstration that there is political will to support families coming together to answer those needs, not just throwing more money at an already broken system.

We, the movers and shakers within our community, need this committee and our government to hear that we have the passion to set the stage for a new story. We just need support in the how-tos. Individuals and families need an unprecedented demonstration of "We hear you. What can we do? Here is our undivided attention. How can we make this work?"

Forgive me. I am an eternal optimist; I drive my husband absolutely batty. But when I become discouraged when not too many things are working these days, I know that I must step up to the plate and say, "Enough!"

I believe that there is a tipping point beginning to emerge, where this has begun to resonate amongst the community. I know that at government-level tables, things aren't working well federally or provincially.

Maybe it's time that we start thinking differently and acting differently. Who wants to be on a board of directors when it is not even a place that is effective any longer?

My last recommendation is dialogue. Talking about critical issues often leads to life-changing events—here's hoping, anyway. I know that my son Lindsey's well-being is a huge concern. There is an absolute need to address the basic and necessary dental care for individuals with special needs. Likely a national oral health strategy is necessary under the Charter of Rights, prior to a lawsuit being commenced. Let's begin the conversation and find a resolution for fair and equitable coverage available under ODSP.

In conclusion, I want to continue to be engaged. I want to support an emerging family movement. I want to see meaningful collaboration across sectors and an unbundling of resources that will enhance the lives of our children and will naturally build capacity within communities. Simple solutions often lie on the other side of complex problems.

I'm going to make sure that the sound is off on this. I'm part of a network of ICANers. Tara's an ICANer and Lindsey's an ICANer. What's been so cool about this: For very minimal dollars—I would probably say zero government dollars, sort of—this network was developed by families going, "Holy Hannah, we've been meeting since 1999, and none of us know each other's kids. For God's sakes, let's get together once per week and just network. Let's try and get those families out of the basement to come out and socialize."

Interjection.

Ms. Debra Johnsen: You remember that—Tara's in a lot of these. There's Tara; there's Tara.

What has emerged from this very simple one-week-per-month informal network has been—Tara's gone camping with one of our volunteers. Two years in a row, a group of girls has gone camping. Right?

Ms. Tara Lennox: Yes.

Ms. Debra Johnsen: Tara's been invited out to dinner, just last week.

Ms. Tara Lennox: No, with Bob.

Ms. Debra Johnsen: With Bob, yes, just recently.

Take your time to look at these slides here because you know what? All the issues you've heard about across the province, there are the movers and shakers in Thunder Bay. Those issues articulated in that wallscape are exactly what you've been hearing across Ontario. I guess what I'm saying from this ICAN! network is that encouraging families somehow—the family network piece—is so important.

There's stories with our pumpkins. Don't do pumpkins too soon because they go mouldy.

Ms. Tara Lennox: And they fall apart.

Ms. Debra Johnsen: And they fall apart.

Ms. Tara Lennox: They do.

Ms. Debra Johnsen: We've seen people who are not normally engaged, engaging and having fun. We've got volunteers who had never been involved in the disability

sector come out and say, “I’m getting more back than I’m giving out.” It has become a perfect, perfect kicking-off point for us.

Anything you want to add? Thank you. I’ll just let that run, and answer any questions.

The Chair (Mrs. Laura Albanese): Thank you very much for your passionate presentation this morning. We do have less than a couple of minutes each for questions. We’ll start with the NDP.

Ms. Cheri DiNovo: Yes, thank you so much for your presentation, and thank you for being part of the solution as well. Circles of support are also operating in my riding. I’ve seen them effectively work through and with Community Living and all sorts of wonderful unique options for families once families are energized, so I want to thank you.

I want to contribute this to Tara because—I feel like I’m hurting the dental saga here—

Ms. Tara Lennox: I can’t have chocolates.

Ms. Cheri DiNovo: Certainly, in terms of the dental care, thank you for bringing that forward. It’s the first time that we’ve heard that piece, and it’s a very critical one. We absolutely need to act on that, I would say immediately. So thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: I too want to join in thanking you for sharing your passionate story. My colleague would like to comment.

Mr. Bill Mauro: Debra, thanks for the presentation. It’s a bit distressing, I must say, to hear the part about the dental. I’m trying to just figure out what’s going on here—not specifically here with us, I guess, as a government, because I know we’ve been part of at least a couple of announcements on expansion—significant expansions, as I came to understand it—on dental care programs.

1120

But maybe there’s a theme here, because you referenced at the beginning that the increases in funding in the sector, that were referenced in the minister’s letter, of \$63 million or whatever the numbers were—you weren’t feeling it on the ground. And the dental money as well, or programming that we’ve rolled out—or at least, I certainly was under the impression we had. There were two separate ones; I forget the names of them now. But you’re not able to find your way—I mean, I understand the piece of ODSP tied to the rates and what the dentists get paid and whether or not they still want to be in the game of providing the service—not “the game,” that’s a poor choice of words. But you know what I mean: being part of the system, in terms of providing the service.

But I even thought, through the public health units, that we had a second program that had expanded access—

Ms. Debra Johnsen: Not any knowledge to me.

Mr. Bill Mauro: Okay.

Ms. Debra Johnsen: I know personally of only one dentist who has the passion, I think, as an advocate—Dr. Mason is well known in Thunder Bay—that it has created such stress in his own personal life—because he’s had to

stop cleanings and whatnot—that he had shut his door, in fact.

The Globe and Mail article suggested possibly specialized clinics. Dr. Mason spoke about lack of being covered for anaesthetic. Well, could Lindsey access his normal office, with anaesthetic, without having to be in an OR room at day surgery at Thunder Bay Regional? I don’t know that answer. Dr. Hettenhausen at Thunder Bay Regional listened to it, and I wasn’t even given to believe that it was an issue of OR time.

It just seems like there’s a vortex of the left hand not knowing what the right hand’s doing. It’s not right. It wouldn’t happen amongst other circles. That’s where the strength of a family network—us coming out of the basement—stopped. It has got to be addressed.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones?

Ms. Sylvia Jones: Debra, thank you for your passion. I loved your three I’s: independent planning and facilitation, individualized funding, and innovation.

I was involved when we were doing some of the transformation agenda. There were a number of us who pushed pretty aggressively for the circles of support, because we have seen anecdotally in our own community how well they have worked when you have that family and community engagement.

So we’re not giving up, and your story will just reinforce the value of what that brings to everyone. Thank you.

Ms. Debra Johnsen: Lindsey’s saying, “Good. Good, you hear.”

Ms. Sylvia Jones: Thank you, Lindsey.

The Chair (Mrs. Laura Albanese): Thank you for being here this morning and for bringing your voice to the table, to our committee.

Ms. Debra Johnsen: Thank you.

THUNDER BAY FAMILY NETWORK

The Chair (Mrs. Laura Albanese): Next we will have the Thunder Bay Family Network, which will do a presentation to the committee. Mr. Paul Meyer?

Yes, Ms. Wong, as we’re waiting for—

Ms. Soo Wong: Madam Chair, while we’re waiting for the next witness, can I ask the researcher to get some data for the committee with respect to the last announcement—it was so recent; I can’t remember the date—last fall, from the Ministry of Health and Long-Term Care, dealing with dental services, and where is the earmark of that, because it was supposed to be expanded programs. The administration of that particular program—my colleague Bill Mauro and I were just talking—my understanding is it was supposed to be administered through the local health unit.

So if we could get some more data on that expanded funding for dental services, and how does that address the last witness’s concern dealing with individuals with developmental disabilities and how they get access to those programs.

The Chair (Mrs. Laura Albanese): If I recall, there was an expansion to an extra 5,000 people, especially children and youth, but perhaps not adults. Thank you.

Welcome.

Ms. Debra Johnsen: Good morning. Here I am again. Not only am I a mom; I'm chair of Thunder Bay Family Network. Passion, passion, passion, 1999 forward.

Today at the table with me is Paul Meyer, one of our board members; and Bob Speer, who is part of one of those networking groups, called the Intentional Living Group. He's also a pretty passionate, cool guy who attends ICAN! with his granddaughter.

I'll do a quick blurb; then Bob Speer will bring up the Intentional Living Group that has emerged from Family Network, and then Paul Meyer will tie up.

We are a family-driven grassroots organization that is dedicated and committed to nurturing the strengths, dreams and enthusiasms of individuals with disabilities, their families and caregivers.

This mission has been constant since our 1999 inception. Over the years, passionate people have tirelessly pursued the goal of building relationships and enhancing community capacity, towards that ever-elusive need for peace of mind.

We've circulated not only our package but the Safe and Secure book that we helped to edit the Ontario version of. If you look closely at it, it provides the six steps. It answers the questions about RDSP. It provides opportunities for how creating a house—and central to all that is networks of support, the values and reasons why networks of support are so important.

The stories you've heard today, and likely in every other community, are based on those very real fears: "What will happen when I'm gone?"

The values guiding our work are simple. We know that families and individuals can best determine their own support needs and that innovative solutions can be discovered when families are engaged. Networks of families are stronger than one family in isolation.

We are continually seeking new and innovative ways to support and nurture families, individuals and communities. The book *Safe and Secure* is central to many of these discussions: tangible steps in how to plan a positive future, one that is built on solid relationships and real opportunity.

We've got various groups that have emerged, and I showcased the photo story of ICAN! because I didn't want to waste the time. I wanted the questions to come after.

Bob Speer will be speaking about the Intentional Living Group.

Mr. Bob Speer: Hello. I'm Bob Speer and I'm a volunteer with the Thunder Bay Family Network. I am a grandfather to a special-needs young lady who is now 18 years old.

Samantha was born weighing only one pound, four ounces. Within a few months, it was determined that she had cerebral palsy and Dandy-Walker. She has been in therapy for years at George Jeffrey Children's Centre

with great success, where she can now walk and attend school. The centre has enriched her life and many other children's who attend the centre. She cannot talk but uses sign language and an iPad to communicate. She will always require 24/7 support for her entire life and is subject to seizures at any given time, and this, hereby, is a big problem.

Imagine you see all around you the challenges that will be facing your son, your daughter, your granddaughter, even many of your friends. Imagine you start exploring and digging a little deeper. You speak about your own wishes, about wanting to live in a setting that is inclusive, one where everyone is supported, their gifts recognized. Imagine what it would look like.

We've been asked by a committee to dream big. Well, this group has been, for the past six months, without knowing that there might be someone who might want to listen beyond the core group of passionate family members and friends.

We've developed a vision. We have imagined a new building with the main floor a buzz of social enterprise, the best club in the town for music and food, which is beyond fantastic. The tourists are even hearing about it as being the place to go. Or as—

Ms. Debra Johnsen: Excuse me, Bob. We would have suggested last night that that's where you would have gone for supper instead of the Prince Arthur. Sorry to interrupt.

Mr. Bob Speer: Or as simple as a coffee shop with various areas of support which complement our intentional living quarters on the upper floors. It could include the recycling shop, the delivery service and the community kitchen.

In order to live here, one must complete our application and agree to established criteria. It might be a mom with young children doing night support, ensuring that two units are tucked in safely, while one of them meets her children off the bus and keeps them occupied making muffins in the community kitchen.

1130

We have found many reports speaking about the crisis that is looming. Our local report by DSSAB on housing and their 12 initiatives and the Ministry of Community and Social Services' own *Ending the Wait* document all talk about housing.

We've seen where the government is supporting social enterprise. It seems as if everyone knows what is needed. We want to start speaking to others, professionals that might support an initiative, but then the word "funding," or lack thereof, stops us in our tracks.

Can a group such as ourselves get support to pull on threads that may challenge existing funding models towards something that is different? Can existing funding dollars be allocated in a different direction to support a concept that supports across age and ability? We are asking this committee to consider allocating resources that will support the growth of innovation that, over the long haul, will provide a community that is engaged in living with intention, supporting all of its citizens.

It is a known fact that many parents with special-needs children and young adults receiving their care and support at home are becoming older, with less energy to provide the proper care most need. Parents, grandparents and families are living with much stress and worry about the outcome of their children if and when they are no longer able to provide the necessary care.

It is important now that plans are made and implemented to provide special housing and care for our special-needs adults. It is time for helping individual groups who want to take the initiative to step up and then plan and implement the goals for intentional living. Groups need access to tools, resources and strategies, and to partner with government and community so dreams will be accomplished and our special people can count on their lives to be enriched.

I do believe this meeting here to listen and receive input from many concerned individuals is a great start, and look forward to the outcome and, hopefully, the necessary help needed to ensure our adult special needs are looked after in the future years.

Thank you.

The Vice-Chair (Mrs. Christine Elliott): Thank you. Yes, sir?

Mr. Paul Meyer: Hi. I'm Paul Meyer, and I'm a board member of the Family Network. I feed off Deb's passion.

I'm sure you're hearing an earful of problems in the systems. I want to talk about what I see as opportunity.

In our community some years ago, back in the 1990s, I was with the Ministry of Community and Social Services. We were closing a facility, and I was charged with helping find placements for people leaving the facility.

We began with the traditional approaches: more group homes and so on. As we came together as a group of agencies with the ministry and talked about it, we challenged each other: "Isn't there a better way?"

We'd heard about this concept of individualized funding which was emerging in BC, learned more about that, and took some of those ideas and adapted them at the community level to something we called the Choices Project. We made it bigger than just people coming out of the facility. With the monies that were moving into the community, we were able to generate a project that would include people from the facility as well as families who were ready for a move from traditional and some that were waiting and had no service. The whole concept was based on a fundamental premise that people plan their own needs before entering the service system.

We had independent facilitation, where the person's family and support network were involved in developing a plan and then negotiating, with the help of a facilitator, the funding for that plan. Thirty families, in that short period of time, were able to participate, and still do enjoy and manage their own support arrangements.

That initiative lost momentum for a variety of reasons that I don't have time to go into right now, but if we fast-forward to today, what I see is this new legislation that contains the nuggets of that same thinking: the key

elements of person-directed planning, the possibility of independent facilitation for those who want it, and even the possibility of direct funding to support the plan that the family and individual develop.

I see underlying this new legislation some fundamental principles that guide us, Deb and I, in our work with the Family Network, and I call it the three Cs. This is a result of a lot of thinking over a lot of years in retirement, when you actually have a chance to sit down and think about life.

We believe passionately that people should have control over their own lives and the lives of their beloved family members. That includes choice. It's even bigger than choice. We learned a lot with the Choices Project. Control, to the extent that any of us have control over our lives—that is fundamental.

Secondly, they have connection beyond paid staff. That's not to knock paid staff; we have many, many good staff in our community who are doing a great job. But there's more to life for these people than just being involved with paid staff. They need connection and opportunity for connection, such as Deb was talking about, with ICAN!, as a simple example.

Thirdly, competence: People are involved in some way, according to whatever ability they have, in something meaningful so that, at the end of the day, their lives have some meaning and they're not just existing and being managed.

When I look at the system, I think we're stuck. All of our resources are tied up in maintaining the current system. On the other hand, I think we have a really enlightened piece of legislation which guides the way to a new way of doing things, and it contains those elements of families having control in planning and arranging their own support systems. But I don't see anything happening. All of the pressure, it seems to me, is focused on the one element that was introduced, and that's the DSOs, where people are getting the assessments, but then the ball stops there; there's no movement. We have a lot of frustration. We've created a huge pressure point across the system, and we're seeing a lot of cynicism from families: "Why bother? It's not going to go anywhere."

It seems to me that the solution lies at the community level, and it begins with families. We need to rethink our whole model of service and supports for individuals with disabilities, using these guiding principles that I think are inherent in the legislation. How do we do that? On the one hand, with the current system, we need what I call—and these are some thoughts that were developed with the help of one of our members sitting in the audience today, from the university—a reinvestment strategy. Many of the points that Lisa raised in her comments from Community Living—rethinking how we provide supports based on this new way of thinking inherent in the legislation; to begin a shift to more individualized approaches.

I'm talking about change, but I'm not talking about chaos. We can't just turn the current system upside down and start all over again, although some of us would like to, including Deb. We start family by family. On a plan

basis, we begin changing the current system and moving to the new page, the new legislation. On that side of the page, I call it an investment strategy. I can't see the government coming up with enough money to maintain the current system and yet pour in a ton of additional funding for this new system that is going to emerge. If any monies do come, and I'm hopeful they will, they need to be focused on this side of the page and not just continue shoring up what we're doing now.

We need to see flexible funding that might be generated from the transformation in the current system moved over to the other side of the page, where it becomes available to more individuals. We need forums where families and communities can come together and talk about and develop their own plans, learn about this new system and how to engage it. That's what Deb's all about.

We need—and this is the tricky one—to move beyond this concept of entitlement: "The state will provide." That's old thinking from institutional days.

1140

There are many families that are willing and able to bring family resources to the table to help develop a plan, to help their young adult children, much as we do with our own, to give them a hand up, a start, not to make them dependent on family for life. Certainly, we have a responsibility to support people with disability, but we're overlooking all of the huge, tremendous potential in communities and families and guys like Bob, who are there doing things with housing, looking at options. We're missing out on all of that.

So how do we start? We start with the community. I'm hearing that across the province there are already some good practices going on. We need to get some of these people together in the same room, at the same table, and talk about how we can develop a framework within whatever guidelines are coming down from the ministry, but we can't wait for this top-loaded plan to filter out. It's got to start at the community. I think we've got the kind of people in this province who have already demonstrated that it's doable and are already doing things, making things happen. We can make it happen.

Lastly, we need more forums for families. As I said, we need opportunities for families. We need to actively encourage it, not just invite a family to a conference or to be a participant at another planning table, but to actually create forums where families have their say and their voice can be heard. It all starts with families having control of the lives of their individuals, their loved ones. If we do anything less, I think we're just wallpapering the room again and I don't think anything is really going to change.

I really wish this committee well in their work and I hope you're hearing the same message but also that you're seeing that opportunity is there. Let's get moving. The train is ready to leave the station. We have communities that are ready to go. Let's get it moving.

Thanks for your time.

Ms. Debra Johnsen: If I can comment: This venue or this opportunity hopefully will help our Thunder Bay

families emerge and create a movement. I'm hopeful that a successful outcome of your work will be Family Network pulling the pieces to bring those families out of the woodwork. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your thorough presentation. That's something that our committee is also looking for—that input from people on the ground such as yourselves. You live it every day and you can teach us. We don't want to tell you what is needed. You have to communicate to us what the need is, so we thank you very much for that.

Unfortunately, we don't have any time left for questions. I just want to convey on behalf of all the members of the committee how much we appreciate your presentation. Thank you very much.

Ms. Debra Johnsen: Thank you.

MR. GEORGE SAARINEN

MS. CHERYL DUCE

The Chair (Mrs. Laura Albanese): We will now hear from George Saارين and Cheryl Duce. Good morning, George and Cheryl. Welcome to our committee.

Mr. George Saارين: Good morning. My name is George Saارين and I'm a front-line worker with Options Northwest Personal Support Services. Cheryl Duce is the director of residential services. I know our time is brief, so I'm just going to get right into the report. I have a short session, and then Cheryl will carry on.

I have met with several MPPs through public consultations. My work with the Federation of Ontario Public Libraries—I know Ms. Albanese from there. I've done deputations with the budget process and I've met MPP Wong during that process.

Just to get into it, I'm a graduate of the developmental services program at Confederation College here in Thunder Bay. I was there from 1978 to 1980, and at that time we were called mental retardation counsellors. My, how terms have changed in the past 30 years.

As well, I am a publicly elected school board trustee with Lakehead Public Schools here in Thunder Bay. We are a school board that welcomes all students. I am not the director; I'm not the superintendent; I'm just one of the independent trustees.

I have concerns, as a trustee, with the lack of supports for individuals with support or special needs who are in our school system. These individuals are in the school system until the age of 21, at which time they are no longer supported by the education system in Ontario. In education, we see shortfalls in special education funding. This is an issue I talk about with MPPs every time I have an opportunity.

We try and offer supports for identified students with needs and have educational assistants work with these students. Unfortunately, the funding dollars do not meet the expectations or the needs, so many students are falling through the cracks and do not get the help they need.

There is a gap or a lack of services for individuals who reach the age of 21. There are few, if any, supports for

these individuals once they leave the school system and enter the community. When they are in school, they have supports, life skills and training opportunities, but these cease at the age of 21.

We have an aging population with our recipients of service. For many years, many of the individuals we supported lived in institutions and were moved in supportive living in the community. Many of the recipients are now in their fifties, sixties, seventies and eighties. Many individuals are dealing with loss of memory, motor skills, mobility and cognitive skills. They experience medical needs which may require hospitalization, and they require supervised supports in a hospital setting due to loss of skills and abilities due to aging issues.

Recipients of service may require 24-hour support in hospital, and many service agencies may not have been provided the funding for such supports. It may be necessary to place our recipients of service in long-term-care facilities, where the caregivers may not be aware of the individual's needs, wants and supports. Once again, the individual may be placed in a strange new environment, which may confuse the individual more.

We are expecting shortfalls of physicians, specialists and dentists in northern Ontario. Many recipients of service face long waits in getting a new doctor or dentist due to the shortages and availability of the professionals. The recipients have needs that need the attention of medical practitioners, as was mentioned earlier. Some of our recipients need to be hospitalized for dental work; for this to be done, long waits are incurred for the surgical time to open up for the dental cleaning and examinations, a simple process that has become complicated. With the shortages of family doctors, the recipients must go to walk-in clinics to get their prescriptions filled and forms for ODSP for equipment such as wheelchairs, devices for supported living, like mechanical lifts, or other supports.

With regard to infrastructure and capital funding, we require more for the operations of the group homes for the recipients. Many of the homes require updates for new roofs, windows, doors, furnaces and ventilation systems. Often, these costs can be astronomical; where do the agencies find the money to make these repairs?

An interesting point that I have experienced with my work is that ODSP ends for recipients of service at age 65. At that time, the individuals are entitled to old age security and the guaranteed income supplement, if the forms are filled out appropriately and in a timely manner, six months before turning 65. However, once ODSP does end, the individuals lose their dental support, dentures and eyes glasses which were previously there through ODSP. The individuals are now responsible to purchase these needs on their own. With the guaranteed income supplement, if the recipient is late in filing their tax return, the GIS is cut off as well.

Through the ODSP income support, we need support for household items such as furniture, bedding, winter clothing and personal items such as winter boots or even appropriate footwear. Often, when the rent and food

expenses are paid, there is very little left for personal needs. Support staff, families and individuals often may go buying clothes and other items in a thrift store or a Salvation Army—again, third-class citizens in Ontario.

We need to support the Special Diet Allowance for recipients of service. We know recipients who have been denied support for the Special Diet Allowance, and purchasing food to help them lead a healthy lifestyle becomes very expensive.

Indexing benefits to the cost of living so that benefits do not decline over time would benefit all recipients of service. Costs are going up everywhere. The base housing allowance needs to be indexed to the actual average cost of the rental accommodation in the community where they reside. Across the province, especially here in the great northwest, costs are higher for rent, hydro, heat, oil, natural gas, city water and sewer. We pay more for food, gas and other supplies, yet ODSP is the same throughout the province.

I would not call it racism, but I certainly see discrimination for the recipients of service, many of whom require specialized equipment such as form-fitting wheelchairs, standers, mechanical lifts and a variety of other supports. These supports come at a huge price, because they are specialized items; they can't be purchased at a Walmart or Target. They have to go to specialty stores such as Shoppers Home Health Care to purchase these medical devices. I appreciate that the Ontario Disability Support Program does support their programs for the wheelchairs or assistive devices once every five years. However, these waits can be longer than five years as well for these individuals.

1150

Ontario public school boards led the initiative for mental health leads and successfully led work with all the ministries and parents' groups to work together for mental health issues across the province.

Others have mentioned the lack of support across the ministries: children and youth services, health, education, housing, and community and social services. The individuals with needs are supported by several ministries, and co-operation and a smooth flow or transition from one service to another would be most helpful to families, agencies and the individuals we support. Let's all talk from the same page and continue success for the individuals we support in their journey of life.

It would be advantageous to have a review panel set up of recipients of service, families, front-line staff and community members or agencies to make recommendations to better meet the financial, emotional, physical and social needs of the individuals we support. I sincerely appreciate the work that this committee is doing across the province and feel this consultation is well overdue but is now happening. Thank you.

Recipients of service have seen many changes in their lives from institutional care to supportive living opportunities. While living in institutions, they had day programs, workshops and recreational programs to enrich their lives. Upon transitioning into the community, many

of these programs have disappeared, and many individuals face long waiting lists to get community supports for recreational opportunities or community programs supporting recipients of service. We heard yesterday about the extensive wait-lists.

However, great gains have been made from the individuals we've supported in the past 50 years. There are reasons to celebrate these successes because the individuals have made the transition from institutions to group homes or Community Living settings. Governments have seen, listened and made changes for the individuals we continue to support. It is my hope that the Select Committee on Developmental Services will listen and act upon the recommendations that are brought up in these hearings to improve the daily life of the individuals we support 24 hours a day, seven days a week, 365 days a year. Thank you.

Ms. Cheryl Duce: Hi. My name is Cheryl Duce, and I'm the director of personal support services with Options Northwest. A lot of the issues that George just mentioned to you are some of the issues that we face. Our organization currently supports 76 adults with developmental disabilities throughout the city of Thunder Bay. We support them in 24-hour supported residential locations. But if you see my submission, the ideas that I present today are also the ideas of those from Superior Greenstone Association for Community Living. They support adults with developmental disabilities in the Greenstone district, which is Geraldton, Nipigon, Red Rock and Pic River.

I just want you to know that I kind of horned in on George's time here. I was just going to submit in writing, but he came to visit me and said he was giving this presentation. A lot of the issues that George has mentioned, because he does work for our organization, are the same issues that I will be presenting to you.

Options Northwest also has a clinical services component to our organization. Not only do we provide residential support, we also provide clinical support. The clinical support is provided to adults with a developmental disability. There's a small amount of funding to provide services to children with a developmental disability, but only those children who have a complex behavioural or medical issue or need.

That's where I kind of lead into my first concern: that there's a lack of group living locations for children with complex medical and behavioural needs. Because of this lack of residential support within the city of Thunder Bay, children with complex medical and behavioural needs are often sent out of town for residential support. We don't have any group living locations for these individuals, for children with developmental disabilities. As we are aware, this is very difficult for the individual and their family. While efforts are made for visits and calls, it isn't easy for some to go to southern Ontario to be with their children. The Residential Placement Advisory Committee, which is a committee that follows up with these children, says some are as young as 10, and they are crying on conference calls because they miss

home and their family. This community has very experienced service providers who can provide the support these children require, but we are told that the cost per day to send children away is more economical than keeping them in Thunder Bay. Once these individuals reach adulthood, many would like to return to their home community of Thunder Bay, but service providers and the community are not aware of their needs. The transition back to Thunder Bay, which we have done on a couple of occasions—transitioned those individuals back to group living residences within our organization—is very difficult due to the cost of travel, problems accessing required information and the time it involves putting the potential new support team in place.

In the end, when you look at the transition cost and the cost of visits for families, is it really more economical? What price do you put on the quality of life for a child and their family? We are all aware of the resulting emotional problems in adulthood when children attended residential schools. If residential locations or treatment centres were developed for children in Thunder Bay, emotional issues would be reduced for the individual and the family. Transitioning to the adult sector could begin at a much earlier age. The adult service provider would be able to get to know the individual by providing respite using purchased services until the child transitions into the adult system, and, I believe, at a much lower cost.

Number two: You said you haven't heard this one yet and now this is the third time you're going to be hearing it, related to ODSP dental benefits. I have actually spoken to dentists within our community who have said that within the city of Thunder Bay—I've talked to dentists within the city of Thunder Bay, who have mentioned that the amount of coverage provided by ODSP dental benefits does not cover the cost of procedures. In order for these dentists to cover their costs, they're required to bill the individual for the difference or—something that's unacceptable to them—to do the work for less. Because they find it very difficult—and this is what one dentist did mention to me: he finds it very difficult to recoup the money from this population for the difference of what the cost is for the ODSP coverage and what the actual cost of the procedure is—they're very reluctant and often refuse to take individuals who are covered on ODSP dental benefits. Our support staff spend a lot of time phoning around, trying to find a dentist, and as soon as they find out they're on ODSP, often they will not even accept the individual.

Others who are fortunate enough to have dentists but require anesthetic and surgery to have dental work done, are put on very long wait-lists waiting for surgery, and we have some that have been on a wait-list for as long as five years. We also have some whom the dentists take off their patient rosters because they haven't seen them in three years and the reason why is because they're waiting for dental surgery—just a real circle. We've even been told by some dentists, "Maybe you should look to Winnipeg to go and get dental surgery done." What would that cost be to the individual and for their support staff?

Also, there's a real lack of physicians available for recipients of service. Some individuals are unable to obtain a regular family physician and rely solely on walk-in clinics, nurse practitioner clinics and the hospital emergency room for health care. This is very difficult for most individuals due to a lack of consistent health care, but particularly difficult for those individuals with complex medical or behavioural issues. I'm sure you're all well aware that some of our individuals with complex behavioural issues require special medications in the controlled drug class. You have to get those medications renewed every three months, and you cannot go to a walk-in clinic. They're not within the scope of a nurse practitioner. They will not renew those prescriptions at any hospital emergency room. Believe me, we've tried all of them. Some individuals with complex behavioural issues also experience medical issues. Without a consistent physician involved in their care to work along with their support team, it is very difficult to try to do a functional assessment to determine the cause of behaviours, which is what we're required to do now under the new policy directives by the ministry.

1200

Many individuals living within the districts—this is for the Greenstone area—have to travel to Thunder Bay for medical care. The appropriate professionals, who are required to review behaviour support plans, as directed in MCSS policy directives, are also not available within this community.

Lack of supported day programs: Most of our recipients of service require support to access their community, many requiring one-on-one support. Because we have limited staffing resources, and because there are four to six individuals residing at each group-living location, individuals have limited access to their community, some less than once a week. There are funded day services available, but because these individuals are supported by an organization in group-living settings, they are on the bottom of the priority list for funded spots.

Purchased support services are available, but due to the cost of these services, which is approximately \$30 to \$36 per hour, very few individuals are able to access this type of support.

Passport funding is available to individuals living within the community. Those individuals, supported in 24-hour residential living locations, again are on the bottom of the priority list for this type of funding.

Aging population and providing palliative care: As individuals age, mobility is often decreased and individuals are faced with diseases of aging. The general population is able to access staffing support and equipment resources to live in their own home as their needs change, or during an acute illness, or at the end of their lives. These resources are not available to organizations. Organizations do not receive extra funding to provide appropriate lifts, accessible washrooms or to make the required renovations, nor do they have the funds to increase staffing, as is often required.

We do put extra staffing in; we go into a deficit because we do that. We have several homes that do support

individuals who have quite high medical needs. The homes are wheelchair-accessible; they have special lifts. But you can't move people around. All of a sudden, somebody in a home, where they were able to walk around their home, but now their mobility is reduced—you can't move them out of their location where they are. So we put extra staffing in to support these individuals when we have to.

Options currently supports an individual who is receiving palliative care in his group home, at the request of his family. This is not the first time we have supported individuals during the end of their life. Because of the age of our population, it is only the start of this type of care. It is in the best interest of those we support to age and receive end-of-life care in their group homes, where they and their families are familiar with staff and roommates, who have become like family.

This reduces funding pressures on the Ministry of Health, as it keeps individuals out of hospitals, long-term care and hospice, where staff are often unfamiliar with how to provide supports to people with developmental disabilities who have complex medical and behavioural needs.

Possibly partnerships can be created with the Ministry of Health to pay for extra staffing and the required equipment and renovations that we organizations put in place during these situations.

We currently have an agreement with the Regional Health Sciences Centre and, at their request, our staff are supporting our recipients of service at the hospital, when they're in the hospital or admitted to the hospital for an extended period of time—

Interjection.

Ms. Cheryl Duce: Oh, sorry. I'm not going to get through. That's okay.

The Chair (Mrs. Laura Albanese): Yes, I'm sorry to interrupt. It's just that we've already gone over the time that has been provided, and we're on a really tight timeline.

Ms. Cheryl Duce: Yes. Sorry.

The Chair (Mrs. Laura Albanese): But at the same time, I want to give you the opportunity to wrap up, at least, with some comments. We do have the presentation, so we can take the time to read it. Just some final comments.

Mr. George Saarinen: I have one comment, when she's done.

The Chair (Mrs. Laura Albanese): Sure.

Ms. Cheryl Duce: You know what? There are many more issues that I have down here, so I was going to submit it in a written submission as it was. Hopefully, you'll read the rest of it.

The Chair (Mrs. Laura Albanese): We will. That is our job.

Mr. George Saarinen: As a school board, we inherited the school of Armstrong when the remote school boards were terminated a few years back. We have a student population of 96 there: 60 are identified.

The Chair (Mrs. Laura Albanese): Okay. Thank you for the written presentation that we will read thoroughly.

It is all very interesting to learn more about the challenges that are faced by the community.

Interjection.

The Chair (Mrs. Laura Albanese): Yes, I know we have to check out of the hotel. All of us are under some time constraints. We are recessed till 1 o'clock. Thank you.

The committee recessed from 1206 to 1300.

LUTHERAN COMMUNITY CARE CENTRE

The Chair (Mrs. Laura Albanese): Our committee is back in session. We are calling on the Lutheran Community Care Centre to come forward. We welcome the executive director to make a presentation to the committee. We thank you for agreeing to come and speak to us. We have heard many people who made presentations here in Thunder Bay reference your centre, so the committee members are eager to find out more about it.

You may begin at any point in time. You have up to 20 minutes for the presentation.

Mr. Michael Maunula: Thank you very much. My name is Michael Maunula. I'm the executive director of the Lutheran Community Care Centre. Its head office is here in Thunder Bay. Our agency serves as the DSO for the northern region. We also administer the Passport program for the northern region and provide case management services for adults with developmental disabilities—that's known as adult protective service workers—for the city of Thunder Bay and along the north shore of Lake Superior to Marathon.

For the programs that cover the entire northern region, the geography is vast. Our southern boundary is the French River, our eastern boundary is around 50 kilometres east of Sudbury, our western boundary is the Manitoba border, and our northern boundary is Hudson Bay.

To serve such a vast region, the DSO, as we call it, short for Developmental Services Ontario, has offices in Dryden, Thunder Bay, Sault Ste. Marie and Sudbury. We utilize videoconferencing technology and Internet voice technology to be as efficient as possible when dealing with the vast distances of our offices and the beneficiaries of our services.

The nine DSOs across the province are fulfilling the role of the application entity as described in the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, its regulations and the policy directives put forth by the Ministry of Community and Social Services. As this legislation went through the committee process of the Legislature, I was impressed with the level of agreement by all the parties on what this legislation should accomplish. To me, there appeared to be agreement on providing a provincially consistent definition of who is eligible for services, the process that would be followed in confirming eligibility, the transformation to a system that was equitable, and the introduction of mechanisms to allow individuals and their

families to have greater involvement in how supports are delivered to them.

You and I know that not all parts of the legislation have been proclaimed; namely, the sections on direct funding and the funding entity. It could be argued that part of the tension we see right now in the service system is that the journey has been started, but part of the process to complete the journey has not been operationalized yet. Nevertheless, the Lutheran Community Care Centre has agreed to start on this journey, and I want to share a bit more on our approach.

We utilize the relationship model of governance and management, and as the name implies, the relationships that our organization has at various levels are given much focus to ensure that they are healthy. We have relationships with our funding ministry, our employees, the beneficiaries of our services and the other service agencies across the north. With our sparse and dispersed population, partnerships are an important part of getting things done. While we have three larger urban centres with larger, and in most cases multiple, agencies, we have many more communities where there is one developmental service provider, very often an association for community living.

As the DSO for the northern region, we need healthy working relationships with those agencies to connect with the individuals and families in need of services for the first time or those experiencing a change in their service needs. The DSOs help articulate the demand for developmental services, show where changes in approaches are needed to respond to new types of supports, and make sure access to a limited resource is done in a fair manner.

We cherish our partnerships with service providers that have good relations with remote First Nation communities so that we can, in culturally appropriate ways, explain the process that must be followed to become eligible for provincially funded developmental services. Because of the remoteness of many First Nation communities in the north, direct funding programs such as Passport are probably the most viable way of providing those supports.

The relationship model places a high importance on certain values. One is the value of affirmation. Affirmation acknowledges the worth and contribution that everyone brings to the achievement of a common goal. In a way, the select committee, through its hearings and invitation to a broad range of parties to present their ideas and concerns, is an act of affirmation. You are hearing multiple perspectives on how to best serve persons with a developmental disability.

Another value of the relationship model is involvement. Involvement allows people the freedom to express their ideas and feelings about matters that affect them. We listen. As the DSO, we may be responsible for performing certain functions in a prescribed fashion; where we can make adjustments based on feedback, we will. We listen to how our partner agencies and the individuals and families we interact with feel about these processes.

System change in an environment of financial constraint can make it hard to discern the issues. Is it the imbalance between the demand for services and resources that are available that is the issue? The DSOs are helping the government quantify the unmet need. Is it the loss of past roles in service delivery that are behind the complaints that the new access-to-service system is not working? There were flaws in the decentralized process of the past. There was inequity. A service system needs time to change, and with the slowdown in the proclamation of all parts of the legislation, all the tools to correct this inequity are not in place yet.

In human services, you can allow yourself to get pretty down about the people who are still waiting for services. I am by no means minimizing the anxiety and the difficulties that these individuals face, and I'm sure you have and will hear a lot about the impact on people's lives.

We and many service providers across this province are helping thousands of people utilize the resources that we have available. We seek out partnerships to be more effective and we challenge each other to be innovative and responsive, and this we will continue to do.

Within our vast northern region, we have what we call four planning tables. One is the Kenora-Rainy River area, the other is the district of Thunder Bay, another is the district of Algoma and the fourth one is the Sudbury-Manitoulin district. As the DSO, on a regular basis we meet with each of those planning tables, and at those planning tables are all the service providers for developmental services. That's one example of how we strive to work in partnership with all our various providers, to discuss the concerns that they have, to get feedback from them about what they perceive is not working well as far as what's in the best interests of the people they serve in their local community.

That is my presentation—rather brief, since I was briefly invited. But I'm certainly open to questions that you may have about the Lutheran Community Care Centre or developmental services, northern region.

The Chair (Mrs. Laura Albanese): Thank you. I will turn it over to Ms. Jones.

Ms. Sylvia Jones: Thank you very much. I do appreciate that we didn't give you a lot of time to prepare, so thank you for appearing.

You also have group homes; is that correct?

Mr. Michael Maunula: No, we do not.

Ms. Sylvia Jones: Okay. Does Lutheran Community Care Centre offer any direct services?

Mr. Michael Maunula: The direct service would be our case management services, so the adult protective service worker.

Ms. Sylvia Jones: Okay. Essentially what you're trying to do is match people with opportunities and housing supports.

Mr. Michael Maunula: That's right. The DSO, when there's an identified vacancy or new resource by the service providers, then matches people who are on the waiting list to those resources.

Ms. Sylvia Jones: And so I'll ask the "elephant in the room" question: How many people are on your waiting list?

Mr. Michael Maunula: We organize the waiting list by what they're asking for—I'll have to refer to another document as far as numbers. For our residential waiting list in the northern region—and this is as of a couple of months ago—we had 657 people waiting for residential supports.

1310

Interjection.

Mr. Michael Maunula: Yes, 657.

For community participation supports, we had 593 people waiting for service in the northern region. For respite services, we had 213. So we have those three waiting lists.

Currently there are not waiting lists for case management services or for clinical services.

Ms. Sylvia Jones: Thank you. You mentioned that because of the nature of so many of your First Nations communities that you serve, the remote nature of them, that they are most often best able to use the Passport Program—which I get, in terms of their remoteness, but having visited, there's also not a lot of opportunity. So how do you match that?

Mr. Michael Maunula: With the Passport dollars that the individual and the family receive, they can engage or hire other people in the community. There may not be another agency that they can purchase a service from, but they could purchase it from a neighbour or someone else who has the ability to provide the various activation or support needs that their son or daughter is requiring. So they're able, in a sense, to act as the employer and purchase those services directly.

Ms. Sylvia Jones: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Ms. Elliott?

Mrs. Christine Elliott: Thank you very much, as well, for coming here on such short notice. I just wanted to follow up on one of the questions my colleague just asked regarding services for First Nations people. What about the assessments? How do you deal with assessments for Passport? How are they conducted? In person? Do you go there? Do they come here? How does that work?

Mr. Michael Maunula: Very often they are done by videoconferencing. All of our four offices that I mentioned have the Ontario telemedicine videoconferencing equipment. Then we link in with—it may be the health clinic in the remote First Nation community that also has that connectivity to videoconferencing. So it's done by videoconferencing.

As you may know, to apply for developmental services, there's an application package, which is an application package as well as a supports intensity scale tool. Those are both done by videoconferencing.

There are times when, if they are coming to a larger community, say, like Sioux Lookout, flying into Sioux Lookout, that we could do it there. In the past, we've had situations where we've agreed to go to their community.

It all depends on whether the ice road is functional at the time, whether you get into that community or not. So you do have to have some flexibility in providing the DSO services in the remote locations.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: Yes. Thank you again for coming on short notice. Have you had an opportunity to read some of the testimony that has come before this committee?

Mr. Michael Maunula: Just very briefly.

Ms. Cheri DiNovo: I have to be frank: What we've heard about DSOs generally—not yours specifically, but DSOs generally—has been very, very negative. What we've heard from people who have come before us is that they see DSOs as simply a hurdle; that it's all about long assessments that aren't really necessary; that once the assessments are done, nothing is forthcoming, usually, in terms of services, except wait-lists, for most people. Some have been told by some folks, and some DSOs, things like, "You have to wait until somebody dies before you get service."

That's what we've been hearing. How would you respond to those concerns?

Mr. Michael Maunula: You have to, I guess, go back to the legislation and why the legislation wanted application entities and a standardized process across the province. Prior to that legislation, how people were determined to be eligible for service varied considerably. Who could sign off to say that that person had a developmental disability was quite different. Now it's very clear and precise as to who is eligible for services.

The identification of their support needs: Again, there would be various tools across the province that were used. The Ministry of Community and Social Services agreed upon a standardized tool, the supports intensity scale tool, for assessing that need. So now it doesn't matter whether you live in Sioux Lookout or Toronto or Ottawa or Kenora; when you are assessed for your needs, the same tool is being prescribed. That is improving the equity and the common knowledge of what people are waiting for. That information then helps the government identify, "Where do we want to redirect our resources"—knowing full well that the resources are limited. Is it more respite that we need as opposed to group living? Is it more direct funding, more Passport funding versus block funding to agencies? It's helping the system evolve.

You're correct: The notion that you go through the application process and in many communities you are then placed on a waiting list—that's not the fault of the DSO. It's just articulating that that is the situation that we are in right now. As those resources become available, the people on the waiting list are all equally measured, evaluated, and there's a standard prioritization process so that you know that those who are in most need or the best match for that service—that that is taking place, as opposed to the person who is the most vocal, the one who

gets their MPP to call the ministry offices and gets a side deal accomplished.

Ms. Cheri DiNovo: We've heard about other jurisdictions—for example, Saskatchewan—where they've eliminated wait-lists, where you cannot be on a wait-list, where services are mandated. Many of the parents that we've heard of have already gone through assessments by the time that they've reached the DSO position, and those assessments—nothing has changed. They can just submit those assessments. Presumably, if you had a system where it was seen as a right to have services rather than a luxury, then you would just take that one assessment that has already been done by a medical diagnostic person. I'm taking time up, but maybe just a quick comment—because I know my colleague has a question as well.

Mr. Michael Maunula: In the province of Ontario, developmental services are voluntary services. They're not mandated services. That's the current legislation.

Miss Monique Taylor: Thank you for the short notice in accommodating us.

How many clients are within your DSO? You have four satellite offices; correct?

Mr. Michael Maunula: Yes.

Miss Monique Taylor: Would you happen to have a number for the entire region?

Mr. Michael Maunula: As far as the number of adults with a developmental disability?

Miss Monique Taylor: Yes. How many clients are within your DSO?

Mr. Michael Maunula: The DSO northern region's target is to complete assessments on about 458 individuals per year. We've been meeting that target for the last few years. The total population in about four or five years' time that we have interacted with may be 3,000 to 4,000 individuals.

Miss Monique Taylor: You're telling me that you have a target of getting 458 new every year? So we still have people who are waiting who can't get to the DSO?

Mr. Michael Maunula: For the people that the DSO interacts with, there is a prioritization process to whom we interact with first, or whom we contact first. Those priorities are transition-aged youth who are turning 18 who have a developmental disability, those who have not received services yet, and those who have changing needs. The people who are already in service will go through the application process, but probably in future years.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): So my understanding is that you really don't know the overall number yet. We don't have sort of a census, let's say.

Mr. Michael Maunula: That is gradually being established—

The Chair (Mrs. Laura Albanese): We're gradually getting there.

Mr. Michael Maunula: There's a provincial database called DSCIS which all the DSOs use, which is currently being ensured that—there's a migration of all the clients

in service in the province of Ontario moving to that database. The migration is still taking place. The cleanup of the data is still in its completion phases, but the ministry is soon at a point to be able to say how many people are being served and what people are waiting for.

1320 The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: Sure, I'll start, and I'm sure my colleagues will have questions as well. Can you talk a little more about the picture that you're gradually getting of the number of people in your region with a developmental disability, and what your role is in assessing the need? Once someone has been identified, it seems as if there is a priority basis in which they will interact with your services. Can you describe that a little bit, in terms of identification and service provision?

Mr. Michael Maunula: In the first two years that the DSOs have been in operation, because we're dealing with new people and often transition-age youth, we are getting a picture of the young people wanting to come into or receive developmental services. They are quite different from, say, the average client that has been with an association or Community Living for many years.

They and their families are used to being in a more integrated setting. They've gone through the school system in an integrated setting, so when they want services for their son or daughter—they want more inclusive settings; they want more generic settings. The group home setting doesn't come first in their mind. A sheltered workshop does not come first in their mind. They want something that's more integrated and inclusive, so you see that in a lot of the people who are coming through the system.

You're also seeing people who, besides their developmental disability, have concurrent issues. It may be a mental health issue. It may be traumatic events in their childhood that they are dealing with.

I think the new people who we are seeing come into the system are a challenge to our traditional service providers. They have to begin to modify their traditional services to respond to that. Hopefully I—

Ms. Mitzie Hunter: No, that's good. Can I ask another question, Ms. Wong?

Ms. Soo Wong: Yes, yes.

Ms. Mitzie Hunter: In the northern region, what are some of the unique conditions that you face, once you identify those needs, in matching those to the services that are available within the community?

Mr. Michael Maunula: I mentioned earlier that in a lot of the communities that we serve, there's just one service provider in town. So a family may come and want their son or daughter to receive residential services or participation supports in that community, and they don't have the luxury of saying, "Well, I'll go to the next community," when the next community is 150 kilometres away. The whole family has to move to receive services from another agency, so the notion of portability is constrained by that.

In small communities, we have fewer recreational and social opportunities for individuals, so you have to be much more creative as to what those community participation supports will be. We have a much higher First Nations population across the north than other parts of Ontario that we have to be cognizant of.

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Soo Wong: How much time do I have, Madam Chair?

The Chair (Mrs. Laura Albanese): A couple of minutes.

Ms. Soo Wong: I have two quick questions, so maybe you can answer them. We've been consistently hearing concerns raised by families that there is fear and intimidation by DSO staff to these families. So my question to you as executive director for your DSO—I only want you to speak to your DSO—is, what support and resources is your agency providing—I'm not saying all the DSOs in Ontario; your particular agency—to make sure that families are not being intimidated and not being fearful when they come with express concerns? What mechanism is your agency providing to make sure that your staff are properly trained and not intimidating those who are recipients of this care?

Mr. Michael Maunula: As far as our staff, as I mentioned, we use the relationship model of governance and management, so all of our staff understand that process, that sense of affirming individuals and involving individuals as much as possible. We closely supervise our staff to make sure that the quality of service that is provided is at an acceptable standard. It's not only in implementing the various provincial tools but also in the way we approach the families. The families know that they can contact the program manager. They can contact myself, and they regularly do.

The other thing that we do as the DSO for the northern region is, when people go through the application process, and we realize that they're going to be placed on a waiting list for some period of time, we want to make sure that they're referred to a case management agency in their community. As I mentioned earlier when we were talking about the waiting list, there isn't a waiting list for case management services. So while they're waiting for, say, the hard service of a residential support from a developmental service agency, the case management agency can send out a social worker to meet with the family and identify, "What are some of the generic resources in our community right now that I can link my son or daughter to?" So things are happening for them to alleviate the stress and the tension of waiting for that eventual, formal service. They're being helped with looking at some more natural supports that are available. We have good linkages with the case management agencies across our region.

Ms. Soo Wong: Okay. My last question, Madam Chair, is that we have heard consistently that there's now an aging population, so what is your relationship with the CCAC and long-term-care facilities to make sure there's

a smooth transition from the DSO through long-term care or whatever services to support the aging needs?

Mr. Michael Maunula: I guess one of the advantages when Lutheran Community Care Centre was chosen as the DSO for the northern region is that we're a multi-service agency. In my introduction, I just mentioned that our services that are available are funded by the Ministry of Community and Social Services. We provide other services such as generic social services, pastoral care in hospitals and homes for the aged, and a street-reach ministry, so through some of our other programs we have quite regular contacts with both the CCAC and the long-term-care facilities. As an agency, we have 30 years of established relationships with those organizations. When you know them and they understand you, you're better able to call them up on the phone and say, "This is the particular client we're dealing with. Besides their developmental disability, they are experiencing health care needs that are rightly within the realm of long-term care." You use those relationships that you've developed over time to work in the best interests of the individual.

They call on us for our help as well, so it's a mutual relationship that you have to develop to make sure that when two service systems are at play and supporting an individual, you gain co-operation at the ground level.

I know that there are protocol agreements between our ministry and the Ministry of Health and Long-Term Care, but those are at a high level. If you have those good relationships on the front line, that often opens doors quicker.

The Chair (Mrs. Laura Albanese): Any other questions?

Ms. Mitzie Hunter: I do have a question. A lot of what we've been hearing about from families directly is that they just didn't know. They didn't know what they were eligible for; they didn't know where to find the help and support. What is your organization doing about communicating to families and making them aware that there is this support available to them in the community that meets their specific need?

Mr. Michael Maunula: When the Lutheran Community Care Centre—in this, I can speak pretty well for all the DSOs—when they were first designated as a developmental service organization, there were tours across all communities within their region describing what the DSO does. That happened in the first six months of our operation, and we had considerable geography to cover. We don't have a massive advertising and marketing budget—and rightly so; our resources are put elsewhere—but there is a provincial DSO website. We also rely on our partner agencies, those ACLs that are in those communities. Naturally the person in Atikokan is going to knock on the association's door there; they're not going to first think of calling a Thunder Bay number or a toll-free number. So we make sure that our partner agencies also can communicate to those individuals and families what the new process is, how to contact the DSO, and we do our best to make sure that it's a seamless process, a toll-free process, and that we have staff

reasonably close to their community. So with the example of Atikokan, they would have someone coming from our Dryden office to meet with them.

1330

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Soo Wong: I have a question, Madam Chair, for the researcher with regard to more data, not a question to the witness.

The Chair (Mrs. Laura Albanese): Any more questions for the witness?

Ms. Soo Wong: No.

The Chair (Mrs. Laura Albanese): I have one final one for the witness and then we can proceed to your question, if you don't mind, Ms. Wong.

I just wanted to know if you had any recommendations and any suggestions for the committee, especially for the region that you serve. If we're putting you on the spot and you prefer to put it in writing and write to us, that's fine as well.

Mr. Michael Maunula: I think that what we feel is most important—and I realize that the ministry is working on the background work that is required to proclaim the rest of the legislation. We would like to see the rest of that legislation proclaimed as soon as it can be proclaimed, because I think that will create the full picture of transformation and will help everyone understand that this is a transformational process. The original legislation was well-thought-out. When all the tools are available, then give it a fair chance to play out. But to criticize it when it's only halfway there and it doesn't have all the tools may be unfair.

The Chair (Mrs. Laura Albanese): What difference would it make to you? What difference would it make in this situation? Just concrete examples.

Mr. Michael Maunula: Well, I guess examples would be that when you have a funding entity and you have direct funding, then for the people who say, "Well, it doesn't make sense for me to send my son or daughter to Thunder Bay where there are more specialized services if I could purchase it with direct funding closer to home, where there will still be the natural supports," it will be of benefit to them. It will be of benefit to the families. They'll feel like they are being listened to and that they don't have to go to large urban centres to receive specialized services.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: A question for research. I'm not sure what parts of this legislation our witness is referring to.

The Chair (Mrs. Laura Albanese): Direct funding.

Ms. Cheri DiNovo: Just more direct funding? There's a piece of legislation here that we're hearing hasn't been put into play, so I would like to hear what that piece is, what piece of legislation.

The Chair (Mrs. Laura Albanese): Yes. I'm going to—so thank you very much for your presentation today. We really appreciate the time that you took to come down and to talk to us very much. Thank you, and keep up the good work.

Mr. Michael Maunula: You're welcome.

The Chair (Mrs. Laura Albanese): Ms. Wong, I know you had a question of the researcher.

Ms. Soo Wong: Yes, thank you. We have consistently heard about the aging population, and today we heard about the need for palliative care. So through you, Madam Chair, to the researcher, I would think the committee would benefit in terms of getting some data from the CCAC in terms of their data on number of admissions, because they are the ones that control the admissions for the long-term-care beds in Ontario. Through the CCAC, by region, I'd like to know the data: How many individuals are currently on the wait-list or currently in long-term care with DD or intellectual disability? That's the first thing.

We also heard this morning, from the last witness, I think it was, about the need for palliative care. We will need data from the LHINs to get the hospice stuff and the funding earmarked for this particular sector.

I believe in one of my requests, Madam Chair, I asked about the concerns dealing with the individual with the capacity review board. Again, we heard this morning the concern raised about the cost for the assessment. So can we pull out that piece of legislation that drove this requirement of assessment?

I also want to hear—

The Chair (Mrs. Laura Albanese): I would believe that it's the same legislation that saw the creation of the DSOs.

Ms. Soo Wong: The DSO?

The Chair (Mrs. Laura Albanese): I would believe so.

Mrs. Christine Elliott: The entity, though, ended up being deemed—becoming a DSO.

Ms. Sylvia Jones: Yes. They didn't call it "DSO" in the legislation.

Ms. Soo Wong: No, no, for the public trustee's office, because the last witness in her presentation, from Options Northwest, talked about an individual without persons to act on their behalf. She talked about the escalating cost, and it's coming through the Office of the Public Guardian and Trustee. That's the AG's office, right?

So my question here is: If someone has a DD diagnosis at age four and now they are 45 and they need to have this reassessment—I mean, they're already financially limited and now have to consider spending \$2,000

to \$5,000. So my question here, Madam Chair, through you to the researcher, is what do we need to do in our deliberation? Because we consistently heard about too many assessments, too much cost, blah, blah, blah.

The Chair (Mrs. Laura Albanese): Too many forms.

Ms. Soo Wong: And now, we have some data here that was presented by one of the witnesses saying that this is a barrier. I want to validate this data. I want to know how we improve it, because very, very clearly the presentation from the AG's office—I know I didn't get too much out, and I certainly know we didn't hear about this piece.

Ms. Erica Simmons: Can I ask for clarification on your previous question? You're asking about funding earmarked for palliative care for people with developmental disabilities?

Ms. Soo Wong: As it relates to the presentation from Options Northwest, because in her written submission—the aging population and providing palliative care. I know hospice funding in Ontario is through the LHINs, so my question here is: What current resources are being earmarked for this growing, aging population? Or are there any?

The Chair (Mrs. Laura Albanese): Yes, Ms. DiNovo?

Ms. Cheri DiNovo: Just further to what Ms. Wong said—I'm just clarifying—this is really similar to the question that we asked about alternative levels of care. How many people with developmental diagnoses or dual diagnoses are in alternative levels of care in hospitals? This directly relates to the other witness who was talking about doing palliative care in the group home rather than in the hospital. One is funded under Comsoc; one is funded under health—you're comparing apples to apples, in other words, so we know what it costs under health. It would be very interesting.

The Chair (Mrs. Laura Albanese): Okay. Well, thank you. This concludes our day here in Thunder Bay. We want to thank everyone who has taken the time to make a presentation, who has taken the time to participate personally in our committee, all the people who are here and who have followed the proceedings of the day. Thank you very much.

We will resume the committee tomorrow at 9:30 in the morning in Moosonee.

The committee adjourned at 1338.

CONTENTS

Wednesday 15 January 2014

Developmental services strategy	DS-347
Ms. Susan Thoms	DS-347
Ms. Deryle Bond	DS-350
Ms. Sandi Boyes	DS-352
Nishnawbe Aski Nation	DS-355
Deputy Grand Chief Goyce Kakegamic	
Mr. Bobby Narcisse	
Community Living Thunder Bay	DS-359
Ms. Lisa Louttit	
Mr. Jordan Pretchuk	
Ryerson University: Reimagining Parenting	DS-362
Ms. Pat Seed	
Ms. Cher McCullough Monteleone	
Ms. Debra Johnsen	DS-364
Thunder Bay Family Network	DS-367
Ms. Debra Johnsen	
Mr. Bob Speer	
Mr. Paul Meyer	
Mr. George Saarinen; Ms. Cheryl Duce	DS-370
Lutheran Community Care Centre	DS-374
Mr. Michael Maunula	

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Select Committee on Developmental Services

Developmental services strategy

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Stratégie de services
aux personnes ayant
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SELECT COMMITTEE ON
DEVELOPMENTAL SERVICESCOMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Friday 17 January 2014

Vendredi 17 janvier 2014

The committee met at 0900 in the Marriott Inn, Ottawa.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning. I call the Select Committee on Developmental Services to order. We are in Ottawa, the nation's capital, so good morning to Ottawa and to all the people who are here in the room to hear our committee today.

MS. DONNA THOMSON

The Chair (Mrs. Laura Albanese): I want to call up our first witness, Donna Thomson. How are you today?

Ms. Donna Thomson: Very well, thank you.

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes for your presentation. If it should be any shorter, that will leave some time for questions or comments by the members of the committee. You may start at any time you feel comfortable.

Ms. Donna Thomson: Thank you for the opportunity to address the Select Committee on Developmental Services this morning. My name is Donna Thomson, and I am a mother, author, advocate and teacher. My husband, Jim Wright, and I have two children, Nicholas and Natalie.

Our son, Nicholas, is 25 years old and has severe, complex disabilities: cerebral palsy, severe scoliosis, epilepsy, mild developmental disability, chronic pain, gastric dysfunction, low vision, severe sleep apnea and osteoporosis. Nicholas's disabilities and chronic health conditions mean that he does not walk, is non-speaking, tube-fed and largely confined to bed. I will tell our story briefly.

Nicholas has had 76 hospitalizations and nine major surgeries. At first, Nick's emergencies were mostly gastro-related, but later, orthopaedic complications related to his hip and spine were the cause of acute pain. Nerve blocks and a surgically implanted spinal cord medication pump were tried to no avail. The nerve blocks caused painful nerve damage, a situation not alleviated by oral medications, including morphine.

About this time, Nicholas was diagnosed with severe, untreatable sleep apnea, and he was discharged to the palliative care team at our children's hospital.

Nicholas's care was impossible for me to manage at home. Overnight, Nicholas required hands-on care every 10 to 20 minutes. My husband and I were exhausted, not only from nursing Nick intensively since his birth, but also from struggling to access whatever limited services and funding we could.

The local coordinated access committee heard our case several times and declined further assistance. We had availed ourselves of the maximum allowable community resources, but that assistance barely touched our needs.

I reported to a community nurse that Nicholas's pain was uncontrolled and the prescribed medication was having little or no effect. When I expressed concern about possibly over-medicating my son to calm the pain, children's aid was called in to investigate our family.

The children's aid caseworker found our family to be loving and responsible, but at risk due to a lack of home help for Nicholas's very high needs. At that point, children's aid became our sponsor in the appeal process, and via the office of the child advocate, our case went to the IMPAC committee.

After several reviews at that level, we finally received a funding package that met our needs. By this time, Nicholas was 17. We chose to direct that funding to the Ottawa Rotary Home, a local children's respite facility. They staffed our home as they would one of their in-patient clients. Like many families today caring for very high-needs loved ones in Ontario, we were forced to fail badly before we were allowed to succeed.

Nicholas is now 25, and the story of his adult support is long, so I won't go into it here. But I would like to share with you that Nicholas has a wonderful life. He lived with us until 2011, at which time he moved into the Ottawa Rotary Home. There, he is thriving with the aid of loving and professional support staff who meet his medical needs and challenge him to pursue his many interests, from his sports blog to supporting his beloved Ottawa Senators hockey team. He has a very busy and fulfilling life that engages family and many friends. In short, Nicholas is an inspiration to all and a contributor to his community.

Since our son was born, I have advocated for the assistance I believed Nick needed. Many service providers, government officials and medical professionals have helped Nick and our family over the years. Everyone

wanted the best for us, yet at times it seemed as if we were speaking different languages. It was as if we were all birds in the same nest but arguing about how to fly. In the end, coordination and co-funding between the Ministry of Health and the Ministry of Community and Social Services provided an answer for our family.

But inter-ministerial coordination alone will not solve the varied and complicated problems of children and adults with disabilities in this province. Ontario's demographics are changing. We have a population that is aging into disability. At the same time, we have the first generation of children with disabilities, raised in family homes, who are surviving and aging. Many of these adults with disabilities will outlive their parents.

There is one constant in all these scenarios: families and family caregivers.

British social change expert Charles Leadbeater said, "Your vantage point determines everything you see." All of you on this committee have heard from people with very different vantage points on Ontario developmental services. I have read through all of the Hansard testimony, and the most frequent question from the committee members was, "If you could change just one thing, what would it be?" The search for a simple answer is perfectly understandable, given the daunting task before the committee, but I believe that nothing will effectively change if we approach this very complex problem by changing just one thing. We require a holistic approach that engages and leverages the assets of all levels of society. That approach needs to address the needs of families with very high medical needs through to milder, but lifelong, support requirements.

None of us know what to do to correct our systemic problems and how to alleviate the stress on families. There are pockets of success in the province and some models of good practice, where families who know what their children need have managed to create solutions. But these few success stories are not well known. We must learn how to scale that success and make those effective solutions available to all who need them.

In order to scale innovative solutions, families, government officials, service providers, the private sector and concerned citizens must develop a shared vantage point. I believe that shared vantage point should be the goal to support families in looking after their loved one with disabilities, from birth to death.

Every family will have a different idea of what kind of life they value for their son or daughter with a disability, and for the family as a whole. As with all families, that idea of what constitutes a good life will change over time. Supporting families in such an individual and fluid way is an extremely complex challenge.

But Ontario has a history of brilliant innovation in the disability sector. The electric wheelchair was invented here. So was the Henson trust.

The RDSP is a perfect example of government working together with families to leverage collective assets with the aim of supporting someone with care needs. The fact that government does not track expenditures of the

person with a disability reflects a recognition on the part of government that people spend money on what they need, in the most efficient way possible. It recognizes that people with disabilities and their families do not belong in the welfare system.

0910

The Special Services at Home program is another model that recognizes the capabilities of families to use their financial assistance creatively and wisely. It is extremely popular and over-subscribed because it supports families in the family home.

The private sector in Ontario can support our families. An innovative corporate social responsibility strategy that rewards employees with caregiving responsibilities to give back to society by looking after their own is one idea worth pursuing.

We need to build on our history of bold innovation in Ontario, and we have the opportunity to do that now. You will be familiar with the new MaRS Discovery District Solutions Lab in Toronto. The mandate of the Solutions Lab reads as follows:

"The MaRS Solutions Lab develops new solutions to improve the lives of people and strengthen the resilience of society. As a change lab, we bring together governments, corporations, non-governmental organizations, foundations, academia and the greater community to help unravel complex problems from a citizen's perspective. We collaborate with partners to develop, prototype and scale new solutions."

The Solutions Lab has already been asked by the Ontario government to propose innovative solutions to the problem of wait-lists for supported housing for adults with developmental disabilities. But housing is only one issue you have heard about in these hearings. The problems facing our families are much more complex and varied. I believe the Solutions Lab is an excellent place to begin seeking answers to our collective needs, but the lens of their inquiry must be much, much broader. The lab should be examining ways in which multiple partners across Ontario society can collaborate to support our families giving care.

Another creative Ontario model of complex problem-solving in society that could assist us find ways of helping families thrive is—it's not an Ontario model, sorry—Grand Challenges Canada. The Grand Challenges model solicits great ideas, tests them out and provides assistance to scale them to the wider population. We need this approach for Ontario families because currently none of us knows how to fix our problems.

The stories you are hearing reflect complex problems that are intertwined with other complex problems. Every solution and good idea in action you have heard about is just that: one good idea for a single individual or a single community. Government is constricted somewhat in its ability to innovate by the imperatives of accountability, transparency and privacy. Those concerns are important to ensure the public trust, but the clock is ticking and Ontario families need solutions now.

The issues before you are not just about services; they are about helping families to thrive. The Ontario govern-

ment must set the tone and agenda for real change in order to provide hope for the future to families supporting a son or daughter with disabilities. This committee has the unique opportunity to provide inspiration for just such change. I have changed my thinking about disability and possibility; I hope you will too.

If there's one thought I'd like to leave you with today, it's about value: how society, the government and everyone values our children with disabilities. There is a lot of talk about our children and how much they cost. I can tell you that my son will never be employable and it costs the taxpayer a great deal of money to maintain his very life. But I would say that the value of our children is directly related to the value of all the families who love all of our children. It's not just about the value; we can value our children as much as we value all of the families who support us. I value my son. I love him. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your presentation this morning. We have about a couple of minutes for each party to comment. Ms. Elliott.

Mrs. Christine Elliott: Thank you very much, Ms. Thomson, for your very thought-provoking presentation today.

I want you to know that we value your son too. We value all of the sons and daughters of all the parents who are here today. We recognize there are a series of concrete problems here that we need to solve: respite, residential issues, day programs and all the rest of it. But more than that, we are trying to see the bigger picture too, and we're trying to make sure that we can incorporate everyone into our society, that everyone has a place and that we recognize the unique abilities of every individual. It's not about what someone contributes in a monetary sense to society; it's about what they contribute to make us all better people, and all of your sons and daughters do that. I just want you to know that we are thinking through that lens as well.

Ms. Donna Thomson: Thank you. I would also like to say that this question is about much, much more than just services. We need a cross-sector approach to address all of the life issues that families face in trying to meet the challenges that they face on a daily basis. Our children are not just about services either.

Mrs. Christine Elliott: We agree. Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much for your story and for sharing your pictures, as well. Absolutely, every single human life is a life of value and dignity.

One of the themes that we've heard over this last week and before that is that this is a system in crisis, veering from crisis to crisis, rather than a system that actually provides—not just about services, but provides a quality of life for families with children with developmental disabilities which all families should experience. We want for your children what we want for our own children. All children should be treated with that degree of dignity. So I want to assure you of that.

Also, we're looking at possible jurisdictional solutions too. There are other jurisdictions that do things different-

ly and, some would say, better, so we're looking at some of those; for example, some that have no waiting lists for services. That might be a way to go. We don't have time to do it now, but if you think about other jurisdictions that do things better, if there are any of those examples, we would love to hear from you as well.

Ms. Donna Thomson: Essex county, for example, had an innovative model that they proposed to this committee that involved the municipality and other organizations. There are good models out there. We don't know how to scale them. We have MaRS Discovery District Solutions Lab, which is prepared to look at complex social problems and figure out ways to scale them.

Single solutions do not work for the range of issues that families face. That's why we need very, very clever, innovative people who are specialists in innovation and design to figure out how we can provide a good life to somebody with a mild developmental disability in northern Ontario and somebody with high, high, complex needs in another part of the province. These are complex problems, and they're going to require a way of going about finding the answers that we have not done before. If you want a solution that you've never had before, you have to approach it in a way that you've never approached it before. That is what I am asking this government to do.

Ms. Cheri DiNovo: We just want to thank you for your expertise. We've heard from a number of families who have provided some phenomenal expertise in this area, so we want to thank you for yours.

The Chair (Mrs. Laura Albanese): We'll go on to Ms. Hunter.

Ms. Mitzie Hunter: Thank you so much for bringing Nicholas's story to our committee and for the ideas that you've suggested.

The MaRS Discovery District: You're right, they are a centre of innovation in this province and we should be tapping into that. I know that the committee has heard that recommendation, and we will follow up and make sure that we bring that to bear as we do our work.

0920

I also want to emphasize that we are looking broadly. A lot of the solutions that have been brought forward go even beyond Ontario into other parts of Canada and even internationally, so our scope is quite broad for the work that we're doing in terms of really looking at strategies that can help to strengthen our system of supports across a lifetime for people with developmental disabilities and dual diagnosis. That's something that we're taking into account as we prepare our recommendations.

Listening to families, to parents, to the community is a key part of the work that we're doing as a committee, as well as to the experts, so we're bringing it all in, and we are committed to doing the best job that we can to improve the system.

The Chair (Mrs. Laura Albanese): Thank you very much, again, from all of us for your presentation this morning.

Ms. Donna Thomson: Thank you.

UNITED FAMILIES OF EASTERN ONTARIO

The Chair (Mrs. Laura Albanese): We will now call upon the United Families of Eastern Ontario to come forward. Good morning.

Ms. Suzanne Jacobson: Good morning.

The Chair (Mrs. Laura Albanese): You can make yourselves comfortable. Whenever you feel ready, you may begin your presentation.

Ms. Jocelyne Brault: Good morning.

The Chair (Mrs. Laura Albanese): If you could please introduce yourselves beforehand.

Ms. Jocelyne Brault: My name is Jocelyne Brault. This is Suzanne Jacobson at my right and Amanda Telford on my left. We are members of the steering committee of United Families of Eastern Ontario, also referred to as UFEO.

UFEO is a coalition of individuals and over 20 family-focused groups committed to improving the lives of all children and adults living with a developmental disability in eastern Ontario. Our membership includes Autism Ontario, the Down Syndrome Association, Family Alliance Ontario, Community Living and the Ontario Rett Syndrome Association, fetal alcohol spectrum and so on, and we represent thousands of individuals and families in our region.

Our vision is for individuals with developmental disabilities to have the same choices and opportunities as the rest of Ontarians. As an organization, our vision is that all people with developmental disabilities have access to the necessary supports and services they need in order to have access to the same opportunities and choices as other Ontarians, thus enabling them to participate to the fullest extent possible in their community and in society throughout their lives.

We are very pleased and very grateful to appear before this select committee today. Although we acknowledge that much has already been said by those appearing before this committee concerning the problems confronting the developmental sector, we would like to summarize our main concerns before discussing some possible solutions.

The system, unfortunately, has become a system of wait-lists and gaps. In the children's system in eastern Ontario, there is a wait-list to get diagnosed of about 24 months. Children are not being identified at the first sign of a developmental delay. After being diagnosed, there is a wait-list to receive treatment, as long as two years, in eastern Ontario. Then, there's a wait-list to receive psychiatric assessment, treatment and continued support at home for children who have a dual diagnosis. Then, there is a wait-list to receive Special Services at Home funding to assist parents to pay for costly services and respite, and it's about five years long. Then, there is another wait-list and gaps to have access to recreational activities and camps, especially for children who have challenging behaviours.

In the adult system in eastern Ontario, there are waiting lists to get assessed by Developmental Services Ontario at the age of 18. Once assessed, there is another

wait-list to have access to funding from the Passport Program that assists people who need support to get integrated and participate in their community once they finish school. There is a waiting list for funded day programs. There is a waiting list for funded residential options, and there is a gap in educational opportunities and training for employment. Then, there's a wait-list and gap in accessing psychiatric assessment, treatment and support, again for people who have a dual diagnosis.

We are all aware, unfortunately, that these problems will only get worse with time if we do nothing.

The establishment of this much-needed select committee shows that our government recognizes this growing problem and is committed to take action. For that we are grateful.

We encourage you, as you consider the policies and programs that are needed, to keep in mind these four principles:

All people with developmental disabilities will have access to the supports and services they need in order to have access to the same choices and opportunities as other Ontarians their age. I'm talking about the right to receive service, just like the right to receive education or the right to receive health care.

All people with developmental disabilities need to be identified immediately—immediately—in order to receive immediate supports and services that they need in order to reach their maximum potential.

All people with developmental disabilities will receive supports and services, from cradle to grave, with no interruptions during all transition periods: from a child entering school, a child entering high school, the adult sector, finishing school and so on and so forth. Right now there are gaps at every transition period with nothing for parents to rely on.

And finally, all people with developmental disabilities need to have the right—they need to have the right—to receive these supports and services throughout their lives in order to plan for a stable future, and continue to have access to the same choices and opportunities as other Ontarians.

These principles are not new; they are enshrined in the UN Convention on the Rights of Persons with Disabilities, which Canada ratified in 2010.

The Ontario government also stated in their 2006 document called Opportunities and Action that, "The fundamental vision is to support people to live as independently as possible in the community and to support the full inclusion of Ontarians with" developmental "disabilities in all aspects of society."

Ontario and Canada are not alone in facing this challenge. There is a very good example of another first-tier nation that has been successfully meeting this challenge for several decades, and that country is also a federal system. That country is Germany, which has had its own share of fiscal obstacles, as Ontario is facing at the moment. We understand there are differences between the two countries, but there are also many similarities, and I would suggest that there are more similarities than differences.

I had the opportunity to go to Germany four years ago to go and have a look at the system. I spent a lot of time in two working environments, two workstations for people who were adults, and also talking to a parent. The highlight of the trip for me was the fact that there was no wait-list.

I was able to ask the parent, “When the child was diagnosed, what happened to her?” There is a team that goes into the family that assesses the needs of the child. After that, the needs of the child are taken care of, whether they need treatment, rehab, speech therapy or respite care as needed for the service. They are taken care of and supported from cradle to grave. When the child enters school, the types of programs they are offered—once the child finishes school, there is a two-year training period, if the child is able, to train to provide to have a job in the workplace. If the child is too severely disabled, they work in a sheltered environment.

Business is on board. By law, businesses of a certain size have to hire so many people with disabilities. If they are not able because of the nature of the industry, they have to provide work for them in the sheltered workshops. If that is not necessary, they have to pay a certain amount of money to help that system continue.

In Germany, they’ve had this system in place for decades. For every German person who you speak to, it’s as—they’ve always been there; it’s as normal as anything else in their community. They know they’re there; they know they work. They are part of society. They are not an outside group; they are really part of society.

I think we need to look at models that would take into consideration the four principles that we have outlined. These models have worked for decades—they’ve ironed out the problems—and we need to look at them. This is probably not the only model that works, but it’s certainly the model that I have experienced. The parents are certainly not stressed the way we are.

0930

I must say that this parent was shocked to find out, in Canada and in Ontario, the amount of wait-lists that we have to contend with. I kept asking her, “Do you have a wait-list to get this treatment program?” She kept saying, “No.”

I kept asking. I said to my friend who interpreted for me, “Please ask her again: ‘What do you mean, there’s no wait-list? Do you not have to wait a few months, a few years?’” She kept looking at me like I was having some difficulty understanding what she was saying to me, and kept telling me, “No, there is no wait-list.” This was at every transition, and it was overwhelming for me to listen to this and to see how much we struggle here.

I understand that everybody wants the best. I know that all members of this committee here want the best for our children; I really, truly believe that. But I truly believe as well that we need to look at other models, to see how we could incorporate them in our system here, to become more efficient and to have a quicker solution to the problem, obviously. Time is of the essence here.

At this point in time, one area that has not been addressed in the committee overview is the significant

difference that early identification and intervention make on cost savings. Suzanne Jacobson will cover that aspect.

Ms. Suzanne Jacobson: Thank you, Jocelyne.

Madam Chair, I sit on this committee representing the children with the United Families of Eastern Ontario. We want to bring to the committee’s attention that it is critically important, in developing your strategy and recommendations, that the committee also focus on early identification and intervention.

In reading your focus elements on education, recreational needs etc., it became immediately apparent that there is a potential for a major gap in strategy of care for persons with a developmental disability.

The gap that we are referring to is from the infant stage to the preschool stage. The earlier a child is identified—at the first signs of a developmental delay—the earlier the child receives effective intervention and the better the life outcomes. Better outcomes mean a reduced cost in the need for services, which of course is a great savings when we’re trying to deal with the huge numbers of children. And it’s not just about the costs. It’s also about the quality of the individual’s life, and the life of the families.

I’d like to share with you briefly the story of my two grandsons, Alex and Nathan.

Alex is nine years old today. He has received many, many services through our public system: his assessment and diagnosis; several blocks of speech therapy; occupational therapy; intensive behavioural intervention, or IBI therapy, at 25 hours a week; and Transitions for six months. He had a full-time aide with him in the regular school system.

All of these services were provided after months and years of wait times. Alex regressed, behaviours became ingrained, and the window of opportunity was missed.

Alex was showing classic signs of autism by 15 months of age, yet he was 20 months before he was identified, and 30 months before he was diagnosed. He waited almost a year for speech therapy, and 10 months for occupational therapy, when he was self-injuring. He was four and a half years old when he began the intensive behavioural intervention therapy. Alex is now in an autism classroom with six children, two aides and one teacher.

The costs of services for Alex in his short lifetime have been great, and it will continue for the rest of his life.

His brother, Nathan, on the other hand, who is now six, was identified at 18 months and diagnosed at 21 months—not because he was more severe, but because he was being assessed through a sibling study every three months. This time, we knew what we needed to do. While privately paid for, Nathan began weekly speech therapy immediately, and I mean a week after he returned from Toronto. Within three months, his language skills had gone from a seven-month-old level to an 18-month-old level. His social skills were blossoming.

By age two, he was in a private intensive behavioural intervention program, for just 12 hours a week. By age four and a half, Nathan no longer required his intensive behaviour therapy program. As he came to the top of the

wait-list for the IBI therapy two years later, he had improved too much; he did not qualify.

While Nathan still has some speech therapy, he is in his local school in grade 1, without an aide, and his recent report card said “strongly performing at the grade 1 level.”

The costs of services for Nathan have been a fraction of those for his older brother, Alex, and Nathan has a real prospect of becoming a very productive member of society.

While this story of Alex and Nathan is on autism, we know that all developmentally delayed children will improve with early identification and effective intervention.

Madam Chair, we encourage you and your committee to expand your area of focus by just two more years in the lifetime of these individuals to include the period from infancy to preschool. Action in this early period will pay positive dividends out of all proportion to the costs of the support and services for this very young age group.

In closing, we applaud this initiative and encourage you, our government and members of all parties that represent Ontarians, to make a conscious decision and put in place the policies and programs that would respect the principles of timely and equal access for all developmentally disabled Ontarians to the supports and services they need and will need throughout the full extent of their lives.

The Chair (Mrs. Laura Albanese): Thank you very much for your thoughtful presentation this morning. We do have just under a couple of minutes for each party. Ms. DiNovo?

Ms. Cheri DiNovo: Thank you so much and thank you again for talking about some of the solutions. The success story of Nathan is a very, very rare one that we've heard in this committee, and it points the way to what we should be doing, absolutely. We are in a crisis model here, where only families in crisis get looked at, where wait-lists are administered and endless assessments are done with no hope of anything coming out of them. We get that this is a system in crisis, so I thank you for that.

I loved your point about moving from what's been considered a welfare discretionary system to a system of entitlement, just like any other health care system. If you walk into a hospital, you get treated. Hopefully, there's no wait-list for that, even though that's become a problem, too. And I liked the German example.

We also heard that in Saskatchewan there is mandated no wait-lists—so a little closer to home. There are lots of examples of how to do it better and I thank you for raising them with us.

The Chair (Mrs. Laura Albanese): Miss Taylor?

Miss Monique Taylor: Thank you so much for your presentation and for being here with us today, and for all of the work that you're doing on a continuous basis, for knowing the need that is out there for families. What a story. We have perfect proof right there between Alex

and Nathan: the differences between receiving those services on time and not.

Definitely, the wait-list is something that we've been hearing about. We are hearing from other jurisdictions that there are no wait-lists and families are succeeding and they're not stressed out like we are here in Ontario. It's really a sad state when we see that with every family we talk to, it's assessment after assessment, it's wait time after wait time, it's one challenge after another challenge. It's unfair, it's not right, and we're determined here to try to make life better for you. Thank you so much again for all of your efforts and for being here with us today.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzi Hunter: Thank you so much, on behalf of the families, for sharing your stories. Certainly, the example that you've given of the German model is one that we have heard and we need to take a closer look at. I also appreciate the recommendation that the supports are from cradle to grave, as you said, and that they should be seamless in terms of the transition points—particularly on the impact on the child as well as the family.

I also have noted the power of early identification, diagnosis and treatment, and, really, the lasting effect that that has on the child, but also on the pressures that it creates on the system itself. We really need to look at it from that whole perspective. I just want to say thank you for that.

I believe my colleague has a comment.

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Suzanne Jacobson: May I just interject briefly here? There is a study from UC Davis that shows this. The research shows they are changing the brain of the child when you intervene right away, and I'm happy to leave that—

The Chair (Mrs. Laura Albanese): Thank you. Ms. Wong?

Ms. Soo Wong: Thank you for sharing your experience and sharing your expertise with our committee.

We know, we have heard and we also hear from the experts about early intervention and early diagnosis, but wearing my previous hat as a professional in health care, there are some parents who are reluctant to have that early diagnosis and that label. From your experience with some of these families, what suggestions or considerations should this committee consider—because not every family is ready for that type of early intervention.

0940

Ms. Amanda Telford: A province-wide public education campaign about the early warning signs of developmental disabilities.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Suzanne Jacobson: I'd like to mention as well that I am in talks with doctors. They're very uncomfortable with making a diagnosis and a referral. They also know there are long wait-lists, and they want to get the help to the child. If we just follow those developmental milestones and if the doctors were made more aware of it at that one-year checkup where we have the Nipissing identification tool that can begin right from two

months—so at that one-year checkup, the doctors are aware of what they need to be looking for. They're not dismissive or, "Oh, let's wait and see. He's a boy, and boys are slower. We can wait." No. If they're not meeting the developmental milestones, you must act immediately.

For those parents—no one wants to hear any concern. I don't want to hear that my child might have a hearing problem, a sight problem or whatever, but if we, at those first signs—if it was a speech problem, then let's link them up right away with a speech pathologist. Let's see what's going on here. Is this a cultural thing? Is this the way the family is at home, or is there something more going on here? We don't treat cancer by saying, "We think you have cancer. Here's your surgery date, your radiation date and your chemo date." We say, "We think you might have cancer," we do further tests, and the course of treatment evolves based on the information that we get. That doesn't happen in autism and in the system for developmental disabilities.

That's a good way to get these parents here. Right now, the savvy parents are the ones whose kids are being picked up, and the others are falling by the wayside.

The Chair (Mrs. Laura Albanese): Mr. MacLaren, I believe you had some comments you wanted to make.

Mr. Jack MacLaren: Thank you. Mrs. Brault, thank you very much for being here, and thank you to the other ladies with you on your committee. I first met you about a year ago when you came into my office. I was most impressed with your presentation, which was very much what you said today, that you have lived with your daughter, who was severely handicapped—as have other people in your group.

In recent years you've had time to do research, work and to try to make things better for others. We all really appreciate that very much. You've gone to the trouble to form your committee. You've gone to the trouble to travel to Germany and come up with ideas, and I know you've considered many other models. You've been working very hard along with all the other ladies who have helped you. You came to Queen's Park and we introduced you to Christine Elliott, our health critic. I just want to thank you for all the work you've done. I want you to know that it has made a big difference. We hear you. Your ideas are great and we will certainly be considering them very thoroughly and completely, and they help us to do a better job.

I want you to know also that this committee—all of us are here because we know we're not doing a good-enough job. We are failing the disabled people and families of Ontario. We hear that across Ontario. We've been on a road trip this week around Ontario, to the north, and not just Toronto and Ottawa. Whether we're in Moosonee, Thunder Bay, Toronto or Ottawa, the problems are the same: Government is not doing a good-enough job. We hear that from you and we've heard that everywhere. We are here, all of us, to try to do better.

I guess I would sum up by saying that as a caring society we have a responsibility to help those who can't

help themselves. I think that sums it up pretty well. Thank you for being here.

Ms. Jocelyne Brault: You're welcome; thank you.

Ms. Amanda Telford: And thank you for the committee.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Jocelyne Brault: I just wanted to add that UFEO has made a video that depicts the life of a family living with a child with a developmental disability. We will submit that with our written presentation. It's four and a half minutes. It's not very long but I think it's very telling.

The Chair (Mrs. Laura Albanese): That would be wonderful. Thank you again for presenting to the whole committee this morning. We really appreciate your ideas and your insight.

Ms. Suzanne Jacobson: Thank you for the opportunity.

FETAL ALCOHOL SPECTRUM DISORDER GROUP OF OTTAWA

The Chair (Mrs. Laura Albanese): We'll call now on the Fetal Alcohol Spectrum Disorder Group of Ottawa. Good morning. Please make yourselves comfortable. As you have heard, you will have up to 20 minutes for the presentation. Please begin by stating your names. You may begin anytime.

Ms. Elspeth Ross: Thank you. My name is Elspeth Ross, and I'm here today with Barbara Sabourin. We represent the Fetal Alcohol Spectrum Disorder Group of Ottawa, not the coalition of Ottawa. I co-facilitate our group with psychologist Dr. Virginia Bourget. We have been meeting at CHEO, the Children's Hospital of Eastern Ontario, since 1999. I am also a member of the FASD Coalition of Ottawa and FASD ONE, Ontario Network of Expertise, two working groups. I work as a volunteer educator in FASD, providing current awareness by emails internationally via the Yahoo listserv FASD-Canadian-News.

Perhaps my best qualification to speak to you today is as a parent. Our story is different from many because in 1981, when we adopted our first son, we were told about prenatal alcohol and advised to look for help. We later adopted a second fetal-alcohol-affected older boy from Saskatchewan. Many birth, foster and adoptive families simply don't realize that their child is affected or has a developmental disability.

We see from your transcripts that four of the ministry people who spoke to this committee mentioned FASD, but only in passing. The speaker for children and youth services mentioned FASD with autism on October 30. On November 13, the person from education spoke of FASD with ADHD. The Attorney General/correctional services spoke of it with mental illness. Aboriginal affairs mentioned one program. No researcher or speaker for agencies such as Community Living has mentioned FASD at all.

We are glad that some of our colleagues have spoken to you about FASD in London and Thunder Bay, and we won't repeat too much. I refer you to our fact sheet, which you're getting, What is Fetal Alcohol Spectrum Disorder?

FASD is an umbrella term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol, and it includes fetal alcohol syndrome. These effects can include lifelong physical, mental and behavioural difficulties and learning disabilities. FASD is a developmental disability. Most people have not FAS, but ARND, alcohol-related neurodevelopmental disorder. People talk well and present well and look like everyone else, but they have invisible brain damage.

The Public Health Agency of Canada has used the prevalence rate of 1 in 100 for FASD since 2005. The annual cost of FASD in Canada has been estimated at approximately \$7.6 billion. See our fact sheet.

No two people with FASD are the same, but they are all at risk for school difficulty, mental health issues, difficulties maintaining employment, and addictions. Common challenges are with executive functioning: judging, planning, delaying gratification, consequences, organization, impulsivity and memory. Supports and services and tailored programming make a difference. People with FASD need an "external brain" to help them with daily life. They have many talents and skills, and we build on these to maximize potential.

My sons with FASD are now 34 and 31. They were labelled with ADHD when they were young and always got special ed, which helped a lot, although it was not always appropriate. We didn't have to fight for it in those days. Both graduated from high school and one graduated from college. Both are good drivers, although one has lost his licence. My older son has never had behavioural problems and was married for about seven years. Both work part-time in summer in brick and stone with the same long-time boss. They live together in a second house on our property. It is not independence, but interdependence. One has ODSP support. One has diabetes, type 2, so there are health concerns.

We're in constant touch and help them with money management, keeping important documents, filling out forms, understanding time, scheduling and reminding about appointments (that's the external brain), taking them to doctors—yes, I go in with them—and buying groceries.

Problems with the law have been minor. A policeman who knew about FAS—yes, one—tore up a summons for my younger son when, at 17, he was caught shoplifting from a store at 2:30 after going there for a job interview at 12 noon. Does that make sense? Impulsivity. We get letters from collection agencies demanding payments for sums like \$237, again for something that my son doesn't know anything about, he says—maybe getting on a bus without paying or something like that. He lost an apartment funded through ODSP because his supposed "friends," met on the street, moved in and caused trouble. Then my son said, "Well, it could happen again."

0950

They are in some ways at the top of the spectrum, although neither is working at the moment. A second house helps, but unfortunately, most families do not have that advantage.

As with other developmental disability families, we also need to plan for the future: Who will look after them in the future?

Our FASD Group of Ottawa and a support group at Wabano aboriginal health centre are the only specific FASD services in Ottawa; both are volunteer. When parents find out there are no designated services for FASD, some are not willing to try for a diagnosis, since they say it would be stigmatizing and would get nothing.

There has been FASD training in Ottawa, but contacting any agency for help will not necessarily get you to the right people.

Parents have to educate themselves about FASD and ask for help for their child's symptoms. As parents, we are training professionals one at a time and need to be vigilant, because professionals often see only the behaviour and not the brain damage.

A professional study from FASD stakeholders, *Moving Forward*, in 2008 found that the biggest needs of families are help with schools, finding respite, help with transition to adult services, finding supported living and employment—sounds familiar to everybody—but found a lack of trained professionals who know and understand FASD.

Most affected people have an average IQ, or even higher, and don't qualify for DSO supports; they're considered high-functioning. We can't get by the gatekeeper in Ottawa—Service Coordination—to get programs.

We need acknowledgement from the province and from agencies that FASD exists. FASD ONE is calling for a provincial FASD strategy. Ontario should take note and work on prevention, because there's going to be more FASD in future. Women are drinking almost as much as men, and binge-drinking is up for young women and those up to 35. Some 50% of pregnancies are unplanned.

The Ontario Select Committee on Mental Health and Addictions, to which five of us in FASD spoke across the province in 2009, had only one line on FASD in its final report, that "individuals with autism, eating disorders, fetal alcohol spectrum disorder, or a dual diagnosis are orphaned by a system that seemingly has no place for them"—page 1.

But the interim report included things that we're putting in our recommendations to you today. On page 31, it says that "FASD has 'orphan' status, as no ministry assumes responsibility for it, and it lacks an OHIP billing code."

Nothing has changed. We need the same services as other families in this province with developmental disabilities. We can provide examples of innovative services from other provinces, where the phrase "developmental disabilities and autism and FASD" has meaning, and Community Living includes help for FASD. Examples

are peer support in Yellowknife and programs in Alberta and BC.

We are heartened that the Journal on Developmental Disabilities from Ontario had a special issue on FASD in 2013, and that NeuroDevNet, which researches brain development, chose to study FASD, autism and cerebral palsy.

Services for people with FASD in Ontario are needed so they can contribute to society as best they can, and this will reduce costs in general.

I will now ask my colleague Barb to speak to you.

Ms. Barbara Sabourin: Thanks, Elspeth. Good morning. I'm Barb Sabourin, and I'm also the mother of someone with FASD.

Knowing that my presentation is public, I have chosen to not use my son's name, so that I can protect his privacy and that of my family.

My son was finally diagnosed with alcohol-related neuro-developmental disorder, ARND, by the genetics clinic at CHEO when he was 16 years old. We tried earlier, but we had not been able to get information about his birth mother's alcohol consumption. The concern at the time when we adopted was that she had taken other substances which are much less teratogenic than alcohol itself.

The requirement was to have documented statements by a health professional that she drank during pregnancy, including estimates of how much and when—not an easy thing to obtain years after going through an adoption, and for many parents, this is impossible to obtain.

In addition, we had to put together a package with recent psychological assessments, which we paid for; an educational assessment, partly done by the school; copies of IEPs and report cards for at least three years; and a questionnaire. That was quite the undertaking and quite the significant package of information that we had to provide. It's not easy to do.

The diagnosis came with a discussion of what our expectations were in terms of services. It was pretty clear that none came with the diagnosis. I knew that, but still felt the diagnosis was important.

Currently, we do not have any services provided, other than getting into ODSP. We've been told that my son qualifies for services through DSO, even though most people with FAS do not—my son does have a dual diagnosis—but we've been waiting almost a year for the intake interview. We don't even have the name of a contact there; the letter informing us of his status was anonymous and unsigned.

I started attending the FASD Group of Ottawa, which Elspeth runs, when my son was about 14. Up until then, we felt alone. We had no support from anyone: not from children's aid, as we had completed the adoption process; not from the schools, who really didn't know how to manage our son; and not from friends, who just didn't understand. That is one of the things about FASD: It's an invisible disability, isn't well understood and is totally isolating.

Just to give you some examples of parenting in the earlier years, I remember going on trips with my son to

visit other family members, because I felt that was the safest environment. I had to hold my son's hand the whole time that we were travelling. If we were on a plane, he was right beside me all the time, not even going to the washroom by himself. If we were in an airport, he was right beside me, holding my hand. Imagine that with someone who has high energy. Really, throughout the years, it was quite tiring for me to travel.

I also remember keeping to a very strict routine for bedtime, because once you change the routine and allow any change, like a later bedtime for a special occasion, it becomes that change every night. My son can't differentiate between the situations.

This sort of reminds me of research done by Dr. James Reynolds at Queen's University on an animal model, with guinea pigs. He had a maze, and then they had to get to the food. The affected guinea pigs could get to the food when he set up the maze to start with, but when he changed the maze—my memory is he said it took, like, 200 times for them to get to the food, compared to the normal guinea pigs, who would adjust their behaviour.

Any change in routine for a child with FASD can cause a total breakdown. There were no sleepovers at friends' houses, no overnight summer camping trips. Daycare providers were picked very carefully, as were camps. The camps from the city of Ottawa, for example, where the children start off in a gym, were a definite no. My son would get overloaded way too easily.

I just want to make a couple of points on education, and I know you've heard from the ministry. Middle school was hell: no differentiation of services, no longer a really defined structure, and no one teacher in charge that I could talk to. Homework was more and more of an issue, and I would get notes at home that would say he hadn't completed whatever task in whatever time, like somehow I could fix it.

No information passes from one teacher to another without the parents being the conduit. Teachers are not required to look at IEPs—even the resource teachers—before the students start, or at any time during the year, even though principals are accountable for implementing these IEPs.

I understand that some improvements have been made, but funding has also been cut. I think that improvements in the education system are definitely needed.

My son has finished school now, as he is over 21. The implementation of the 21 rule is a little different than you might think, as a parent. It doesn't mean you can go until the day you turn 21. It means that if you turn 21 during the school year, you can't start the school year, so your end date is actually the term before you thought it was.

He had a transition plan, which is like a project plan. The goal statement for my son was "to prepare students for entry to the world of work upon graduation from high school, and, as appropriate for each individual, to prepare them for independent living and employment etc."

Then there was a list of actions, and all the actions were things the school had already been doing, like having co-op placements and work placements. It really

didn't help at all. That is definitely an area that could use improvement.

We're now in limbo. My son lives at home. He is not currently employed or attending any skills programs. We're waiting for the DSO meeting to see what that brings. We're trying to avoid a crisis before that, even though that may be the only way to get service. I don't know that my family can survive another crisis.

You've heard about the cause of FASD and the prevalence, with about one in 100 births affected. That's about the same as hepatitis C in Canada, yet look at the service provided for people with hepatitis C.

That means there are probably about 120,000 or so people in Ontario who are affected by FASD, and about 800 in Ottawa alone. So why am I always feeling like I'm the first to ask for something, and why do I always have to educate every caregiver about what FASD is?

It being a spectrum, like the autism spectrum, individuals will have different levels of ability and disability, but some of the key areas are executive functioning, decision-making and judgment. This means that on the severe end of the spectrum, individuals with FASD need constant supervision so that they don't harm themselves or others. At the other end of spectrum, individuals may just need a caring adult to listen to them and give suggestions on things, or to check in on them from time to time.

1000

Now, in front of you, on the first page, you have our recommendations. I'll just go through them briefly.

The first is to acknowledge that FASD is a developmental disability and to include FASD explicitly every time there is a list of examples of developmental disabilities. This would make all the services accessible for those with FASD. We have enough hurdles to jump over without adding that one every single time.

The second is to recommend more FASD diagnostic centres and to fund them so that getting a diagnosis is accessible. The only clinic here is the genetics clinic at CHEO.

The third is, as with the diagnostic centres, to provide for qualified caregivers to provide respite care so that these struggling families can get a bit of a break and can continue to parent these children; similarly, to provide for assistance with the transition from school to post-school, so that these individuals can become contributing members of society and live as independently as possible.

The fourth is to ensure the education system treats FASD as what it is: a developmental disability caused by organic brain damage and not as a behavioural problem. Time-limited interventions, such as the section 23 classes, are not sufficient, as these individuals have permanent, organic brain damage.

Also, I'd suggest doing an evaluation of the education system to see if it's really meeting its goals, including looking at examples of IEPs, talking to school councils for schools with a high proportion of students with developmental disabilities, such as Sir Guy Carleton Secondary School here in Ottawa.

The fifth is to provide better coordination of services, and I know this is part of your mandate. This includes reducing the number of assessments required for each of the different services. The ministries you've heard from, or will hear from, should work together and not in isolation. This is especially important as individuals with developmental disabilities become more independent. For more details, as Elspeth mentioned, I think, look at the Select Committee on Mental Health and Addictions report. I know you've already recommended that—that you will include that in your research.

The sixth is to create a way for Ontarians to know what services are available and how to access them, other than by talking to other parents. There are so many different rules, access points, forms, assessment requirements etc. that it's really hard to figure them all out, and you might miss a service that might be available to you.

The seventh is to insist that curricula for all health professions regulated by the province—and I would go a little bit broader—include training on FASD. Continuing education should be provided for those who are already certified. Training is available, and has been provided here in Ottawa, and yet it's very hard, as Elspeth said, to find a caregiver who has that training.

Our eighth and final recommendation is to recommend the creation and funding of more case manager positions to help people with developmental disabilities. These would be especially useful for individuals with FASD who need an external brain or scaffold to cope with the requirements of everyday life.

To close, thank you for the opportunity to speak to you today and for the work that you're all doing. We look forward to reading your report.

The Chair (Mrs. Laura Albanese): We want to particularly thank you for presenting to our committee this morning. Unfortunately, we don't have time left over for any comments from all the different members, but we will take your recommendations into consideration. FASD has been a concern that has been brought to our attention throughout the different hearings. I know there are some members who are very interested in learning more about that. Thank you very much.

MULTIDIMENSIONAL ASSESSMENT OF PROVIDERS AND SYSTEMS

The Chair (Mrs. Laura Albanese): We'll now call on the Multidimensional Assessment of Providers and Systems, MAPS, program of research. Is that correct?

Ms. Hélène Ouellette-Kuntz: That's correct. Thank you.

The Chair (Mrs. Laura Albanese): Good morning.
Ms. Hélène Ouellette-Kuntz: Good morning. I'm Hélène Ouellette-Kuntz from Queen's University. I'm here today with Virginie Cobigo from the University of Ottawa. I want to thank you for this opportunity to share our research with you.

I want to begin by ensuring you that we do recognize the importance of increasing investment in services.

What we are going to be talking to you about is a research program and the importance of investing in the creation of evidence and having evidence to monitor the effectiveness, the impact, of policy changes or service changes.

MAPS stands for the Multidimensional Assessment of Providers and Systems. I want to give you a little bit of background to help you understand who we are and what we do and, most importantly, why we do this.

The Ministry of Community and Social Services had a long history of funding, teaching, service and research at Queen's University, and I believe you'll hear about that later this morning, mainly in support of Rideau Regional Centre. With the closure of Rideau, the ministry committed three additional years of research funding to Queen's University. In order to obtain those research funds at Queen's, we had to submit a proposal for how these funds would actually help the ministry in transformation, in support of new policy directives.

I took the lead and brought together an excellent team of academics from diverse fields and multiple universities. As you can see on this slide, there are five universities from across the province represented on our research program.

The other point I'd like to make is, our research team has the capacity to do research in French and English and around looking at the realities for different communities across the province.

What we proposed to the ministry nearly five years ago was to work with the policy, research and analysis branch, as well as the community and developmental services branch, regional offices, transfer payment agencies, families and individuals with developmental disabilities to inform the assessment of services and supports for adults with developmental disabilities in Ontario. The timing of our proposal corresponded with the adoption of the services and supports to promote the social inclusion of persons with developmental disabilities, so that served to focus our work.

We developed conceptual models based on literature reviews and extensive consultations, and those consultations included families and individuals with disabilities.

We also explored specific policy areas through applied research to highlight how existing data could be used or new data collected in the context of an assessment of quality across the sector. The specific areas we explored are described, along with some of the findings in the briefing notes that we sent to the committee. Scientific papers that we've published and reports that we've produced for the ministry are all available on our website.

We are the first group to have had the opportunity to explore these issues at the provincial level and in collaboration with policy-makers and service providers. Therefore, we have information that is relevant to policy-making and service planning at the provincial level.

The focus of today's presentation will not be on those specific research projects but rather on the main, overarching aim of the MAPS program, which was to identify how best to monitor the quality of developmental

services in Ontario. We think this is critical to any kind of system improvement effort.

We learned that some jurisdictions have committed time and resources to measuring quality across their systems and are having a significant impact on services. In the United States, agencies can opt to collect data on key indicators for a sample of service recipients that are then submitted to a third party, to a research institute, which analyzes the data such that states can compare their achievements on policy-relevant issues. The program, which is called National Core Indicators, was established in 1997. Americans acknowledge that this long-standing program provides the ability to create benchmarks in national norms, compares change over time and across regions, allows the development and measurement of strategic goals, and enhances system transparency.

In the Netherlands, government-funded services must report on the quality of their services. They can choose an approach from a number that are approved by the government. In one such approach, the Quality Qube, which is included and described in our report, provides the organizations with a framework and, again, third-party support for this evaluation. But the targeted priority areas that any agency adopts are developed in consultation with service users, families and staff within those agencies.

The lessons learned from that Dutch model include the importance of monitoring outcomes for the service users, not just processes or outputs of services. It also acknowledges the importance of representing the perspectives of all stakeholders—the individuals, the families, the staff that work within the agencies—and of reporting that is tailored to the needs of those who will use the information to then improve services.

While neither of those approaches fits perfectly for our Ontario context, they were quite informative, and our stakeholders here in Ontario, which included family members, agencies and the ministry, to whom we presented the models were quite enthusiastic about them.

1010

As previously said, we reviewed existing data and data collection practices that could inform quality improvement. The first thing to recognize is that all information that is needed cannot be found in one place or through one mechanism. As you've heard, in order to examine age-related transitions, which are quite important, data are needed from different sectors. Within the DS sector, much data are collected. Many service agencies routinely engage in user satisfaction surveys and collect or collate additional information for accreditation or continuous quality improvement purposes. And all agencies report on compliance to quality assurance measures to the ministry.

In addition to collecting quality assurance compliance information from all service agencies, MCSS also collects information on recipients of the Ontario Disability Support Program and Ontario Works. Recently, MCSS has invested in DSCIS, a new data system which you may have heard about, and over time DSCIS will provide

information on all individuals eligible for adult developmental services and supports.

Through examination of current-day collection practices and consultations with stakeholders, gaps and limitations in the current systems—and they are plural: systems—of data collection were identified. Most importantly, Ontario stakeholders have told us that there is a lack of information on how to improve the services. The data that are available generally fail to inform where and how improvements could be made and are not reported in a timely and relevant manner to those who could act upon the developed knowledge.

I'll turn it over to Virginie.

Dr. Virginie Cobigo: To address these concerns from the stakeholders, MAPS would like to propose a way for which you assess the quality of the services for adults with intellectual disabilities in Ontario. This is to engage in a continuous quality improvement approach, which means that data is collected on an ongoing basis and is reported to those who can act upon the knowledge developed.

Our recommendations are to improve data collection and utilization, and develop the capacity of the developmental services system to collaborate with all stakeholders and be responsive to the knowledge developed through data collection.

Through the MAPS work, we have developed 150 indicators relevant to several priorities and service planning. We recognize that our 150 indicators are a lot to implement quickly, but as Hélène mentioned, Ontario has the capacity to use some of the data that is currently collected for quality improvement purposes immediately. Other data would require additional efforts or linkages across sectors, programs or agencies.

I would like to say that today we have decided to focus on some of our indicators that are more relevant to the priorities of your committee to illustrate how data collection could be improved in Ontario. Current activities assessing the quality of services for adults with intellectual disabilities tend, right now, to focus on the compliance processes and outputs, as Hélène mentioned, when Ontarians with intellectual disabilities, their families and service providers call for a shift to measuring the impact of the services on the lives of persons with intellectual disabilities. We present here in red some findings from the MAPS study.

Of about 200 parents requesting services in all DSOs in the province, as you can see, one of our indicators is the percentage of parents who report that their son or daughter has community activities, and only 66% of the parents answered positively.

Another indicator is the percentage of parents reporting that their son or daughter has friends who are not paid to be their friends or are not family members, and only half of the parents think that their son or daughter has a friend.

These numbers illustrate sad stories of social isolation, but they gain further meaning when compared with other jurisdictions. These indicators are taken from the Nation-

al Core Indicators and thus allow for comparisons with US states, but if we would be to standardize data collection in Ontario, then it would allow us to compare across regions in Ontario, which is not currently possible.

We also learned from our consultation that it would be important to provide information on what really matters for persons with intellectual disabilities and their parents or friends. For example, we asked the question to persons with intellectual and developmental disabilities: What should be our target when trying to improve their social inclusion? They said that what really matters is when they feel they belong to groups of friends and acquaintances. But belonging to groups of friends is not currently captured in the data collection in Ontario, so we don't know about what really matters for the service users.

Collecting data is not enough if it is not used for service improvement. In a continuous quality improvement approach, all stakeholders should and must be responsive to the knowledge developed. Data is currently collected on the number of persons requesting services, the number of persons receiving services, their waiting times etc. For example, in our study on the parents requesting services, we found that only 19% of them received services within six months. The most commonly received services were community participation, support respite and residential supports. This information is relevant and useful for policy planning and service assessment, but it would be more useful if there was a process by which we could report on this information to those who can act upon the knowledge developed. Currently in Ontario, there is no such process.

Furthermore, Ontarians with intellectual disabilities and their families urge the developmental services system to consider their perspective when assessing the quality of the services, rather than focusing on whether or not we comply with standards and policies. The waiting times are important information, as we just said—but would provide a better appreciation of the quality of the services if we knew how the services are responsive to families in distress. For example, in our study on parents requesting services, we surveyed them on their levels of stress. Some 23% of the parents we interviewed were reporting high levels of distress six months after requesting services, and 42% of them reported moderate levels of distress after six months.

Services for persons with intellectual disabilities, as Hélène mentioned, are not the responsibility of one single ministry or one service provider. Therefore, improved data collection and utilization would require linkages between multiple data sources, as well as inter-ministerial collaboration and communication. At time of transitions, it is even more important. For example, when we would like to know about the work needs of young adults with intellectual disabilities, we would require linkages between the education sector and the developmental services sector, which is not currently possible in Ontario. In the absence of such linkages, we still can serve the users of developmental services or recipients of ODSP.

As part of MAPS, we surveyed about 2,000 recipients of ODSP who were identified as having intellectual and

developmental disabilities, and we asked them about their work experiences and their education attendance. Some 73% of the sample reported that they attended high school, but this number is not by itself very informative. What is most informative is to break it down by age groups and to see the trends in the data. You can see with the trends in the data that policies around inclusive education have an impact on the attendance in school of persons with intellectual disabilities. This also demonstrates the importance of observing trends rather than looking at overall measures, and observing change over time and understanding the impact of policies and service planning.

Variations in regions are also important. For example, we learned that persons with intellectual disabilities in rural regions are less likely to have gone to high school.

Finally, another way of showing that overall measures don't tell an accurate story is to look at numbers of work experience in adults with intellectual disabilities. If you look at these numbers, you could say that 40% of adults with intellectual disabilities have worked for minimum wage or above—but this is lifetime experience. We know from our data that most of them didn't keep their job for long. So better indicators of the quality of the services would be to look at job tenure over time, as well as wage levels—track them over time and compare them with local and international benchmarks.

1020

Ms. Hélène Ouellette-Kuntz: So, as shown, some data does exist. There are significant gaps, however, if we wish to understand the impact of policy and services on people's lives. There's no way to measure the effect of policy change such as the recent transformation of the sector and changes to come.

There's a need to build capacity; improvements to data collection and utilization are crucial for transparency and accountability. The ministry is supporting MAPS for an additional year to work with agencies and data holders to move this agenda. A long-term commitment is, however, required to reach this objective.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you for being here this morning, for coming here. We have about a minute for each party to comment. I believe it's the government's turn to start.

Ms. Mitzie Hunter: Impossible to do in a minute, Madam Chair.

The Chair (Mrs. Laura Albanese): You're going to have to try.

Ms. Mitzie Hunter: I thank you for your presentation. It does warrant further consideration, and I'm glad to see that it's already embedded in the ministry's work.

The focus that you wanted to put on it was on the sense of belonging. What is the most important way to do that? I'm even looking at your slide that looks at productivity, and I see volunteerism is very high. That is a way to achieve belonging. So I just want to get your sense of what is the best way to track that.

Dr. Virginie Cobigo: There are proxies we could use, such as participation in different activities. But you could participate in activities and not feel any belonging to the people who are around you. You can go to work and not feel any belonging to your workplace or your colleagues.

The perception of persons with intellectual disabilities on how they feel in their community would be very important to capture to get a real picture of their inclusion experiences. However, it's more costly and more difficult to get data from persons with intellectual disabilities, so it would require additional considerations. But it is feasible, as we have demonstrated through the MAPS work.

The Chair (Mrs. Laura Albanese): Now Ms. Jones.

Ms. Sylvia Jones: Thank you. I have a specific question related to page 5, which is your thermometer. I want to make sure that I understood you correctly. Number 10 was, "I can't do it anymore." Was that the 23%?

Dr. Virginie Cobigo: It's the high distress level.

Ms. Sylvia Jones: To me, "I can't do it anymore" is crisis. So 23% of your study—

Ms. Hélène Ouellette-Kuntz: —are in or approaching crisis. This is likely an underestimate, because these are people who participated in this study, so they had to feel well enough to do so.

When we look at people who engaged in our study, our rate was 33%, but when we get to six months and who's still in the study, the percentage drops down. I think it's showing that we are losing people who are too distressed to remain involved.

Ms. Sylvia Jones: Not surprising.

My other question is, can you share with the committee the cost of your study and the timeline?

Ms. Hélène Ouellette-Kuntz: We received three years of funding at \$400,000 a year. It included the conceptual work as well as the specific project, such as the ODSP survey of 2,000 individuals, follow-up of families over a two-year period, staff surveys that were done and other components. There were many, many different activities undertaken.

Ms. Sylvia Jones: Thank you.

Interjection.

Ms. Hélène Ouellette-Kuntz: Good point, Virginie. An important thing to recognize is that our contribution as faculty members within universities is not counted in that. We are already paid to do our work, and this is part of our work.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you for the work you've done. It's imperative that we have data collection if we're going to move forward. Some of those figures are staggering, and they basically buttress what we're hearing, really anecdotally, through this committee's work over the last week and the next. So it's interesting to see that what we're hearing is what you're finding statistically. It's also sad that it has taken this long to get it from you.

Hopefully, we can make that investment pay off to the parents, because I can see some parents who would like to have \$400,000 coming their way, too. So, hopefully, this is an investment that produces results in the long term. Thank you.

The Chair (Mrs. Laura Albanese): Thanks once again for being here today.

MS. JOYCE RIVINGTON

The Chair (Mrs. Laura Albanese): We'll call now on Ms. Joyce Rivington. Good morning. I know we are running a few minutes behind, but it should be okay.

Ms. Joyce Rivington: Good morning, My name is Joyce Rivington. I have my friend Barbara King with me because my voice is going this morning, so if it gives out, she will continue.

The Chair (Mrs. Laura Albanese): That's fine. You may begin anytime.

Ms. Joyce Rivington: Okay. I would like to thank the select committee for giving individuals with developmental disabilities and their family members the opportunity to have a voice.

I live in a rural area, in Carleton Place, in Lanark county. My husband and I are in our mid-sixties and have three children. The youngest, Ryan, was born on January 18, 1978.

Over the past 36 years, the largest and most difficult hurdles we have had to overcome stemmed from attitudinal barriers, imposed limitations, intolerance, and systems' resistance to change. Inspiration and strength have come from the knowledge and support of families who, like us, had vision and hope. We do not want our children's disability to shape and define their lives. We want them to have a good life.

I brought a couple of pictures here to give you an idea of what I think is a good life for my child.

What I wanted for my son was that he would have experiences that all children have: to participate in birthday parties, school field trips and grade 12 graduation. He has continued to do those things today. I'd like to share the journey of how I acquired that, and at the same time reinforce the fear and concern that we all have for what has occurred and continues to occur in developmental services in Ontario.

When Ryan was born I sensed from the beginning that there was something wrong. He was admitted to CHEO for testing, resulting in a diagnosis of "developmental delay of unknown etiology and failure to thrive," and the neurologist telling me, "There are places for children like this." This comment was the first indicator to me that children with developmental disabilities are not valued.

The doctor at the developmental clinic had a softer touch and said, "Take him home and love him." My idea of love was putting love into action. I researched information and found out about the importance of sensory motor stimulation—Doman-Delacato brain patterning. This involved enlisting volunteers from the community, which I co-ordinated. People who came to help Ryan got

to know him and care about him. We continued with the program for three years and kept his muscles from atrophying.

Having been born in the late 1970s gave Ryan the advantage of the infant stimulation program, Special Services at Home, and an integrated preschool program, the first in Lanark county.

By age five, Ryan was not walking, only weighed 22 pounds, and was not able to gain weight. His physician sent us to SickKids in Toronto to begin the nasogastric tube feeding program. After only two weeks on the supplementary feeding program, which we did at home, he started to take his first steps. During this stay at SickKids he was also diagnosed with a rare genetic syndrome.

At age five, Ryan was also non-verbal. By chance, a support worker started him on the McGinnis Association Method of teaching speech and language, which was used at Sagonaska School, a Ministry of Education demonstration school in the province. With a great deal of intervention, practice and consistency, he began to make individual sounds. Despite severe oral motor problems, there was clear evidence that Ryan was making significant gains. The speech pathologist who monitored Ryan's program did not agree with the method and instructed the worker to discontinue the program. The situation was one of the most disheartening and unbelievable experiences I had encountered. Ryan was being denied the potential opportunity to acquire speech as a means of communication. It was a battle, but was only a warm-up to the battles we would face to acquire an inclusive education for Ryan.

The Ministry of Community and Social Services was promoting integration at preschool. When it came time for Ryan to register for school, an employee from the local social service agency explained to me that there were two choices: either send him to the TMR school in Smiths Falls or the TMR school in Almonte. I responded that Ryan was going to the same school that his sister and brother went to in Carleton Place, and she told me that that wouldn't happen in Lanark county. To make a long story short, Ryan did attend his community school in Carleton Place, but it was a gruelling process, to say the least.

The Ministry of Community and Social Services regional office in Kingston was supportive of parents like us. Actually, two program supervisors offered to help me develop a statement of needs identifying details of the type of support that Ryan would require to be successful in an integrated school placement.

1030

I just want to interject here and say that I feel fortunate that I lived in MCSS South East Region because I believe there have been quite a few ministry employees who were exemplary, who understood the vision and went out of their way to help families that wanted more flexibility, choice and inclusion for their children.

Ryan started elementary school just as the Education Act changed in 1984-85 and the IPRC process came into

effect. I am sure we set a record for the number of IPRCs held in one year. It was all worth it, even though it was an extremely painful process. Ryan gained an inclusive education, not without our share of tears and glitches.

I was a member of the Lanark county special education committee, SEAC. We had a strong group of parents on the committee. We worked with organizations to promote inclusion, and organized workshops and joint conferences. We also promoted Circle of Friends, and Ryan had a circle of friends in elementary school and high school.

I was involved in developing Ryan's individual education plan to ensure consistency and continuity. In 1995, going from elementary school to high school, I requested that a transition plan be developed utilizing strategies that had enabled Ryan to be successful, and be carried out in high school.

The high school was a bit apprehensive at first, but they did a great job. Ryan also had the benefit of having a great educational assistant who moved with him from elementary school to high school. I think one of the most memorable and gratifying experiences was watching Ryan take part in a Christmas band concert. There were some people in the audience with tears in their eyes. It was an amazing experience and a true example of inclusion.

During Ryan's last couple of years of high school, I requested that he have co-op placements. This was something new for them, and by the end of high school, he had two volunteer job placements in the community, which have continued to the present. At the end of high school, Ryan had a concrete and meaningful transition plan for life after school.

Ryan also attended his high school prom in Hull. A mother of one of the girls who was in Ryan's circle of friends offered to be a chaperone with me for the event. When true inclusion and acceptance works, it works, and it is truly amazing to witness.

The end of school led to the next big hurdle. Ryan was in the highest funding support category for exceptional students. He was now moving from the education system back to the Ministry of Community and Social Services. In order to receive funding in Lanark county, a social services organization had to present the individual to the service providers' table. I requested that I present Ryan's case. This created resistance because it was not a common practice in Lanark county. I presented an individual plan which required money to implement. I was told that there was no money. I received a letter from the service providers' table advising me that they could possibly piece together support translating into attending segregated programs, which was all that existed in Lanark county.

What concerned me about the process was that individuals who didn't understand and did not really know Ryan were participating in making life decisions about the direction Ryan's life would take, and they would not have to live with the outcome of the decisions they were making about his life. This is how and where people with

developmental disabilities lose their ability to choose what kinds and types of support and services they want and need. Decisions are not based on needs, wishes, dreams, goals. They are based on who is in crisis and where there is a vacancy.

What was equally disturbing to me was that from 1984 to 1999, when Ryan graduated from high school, the social services system at the local level had not changed or progressed in 16 years. MCSS started infant stimulation programs, SSAH, integrated preschool, and then things just seemed to stop—an entire system stuck in the past.

I am thankful that system limitations were not able to limit Ryan's potential. Today, he is a self-confident and happy person. We are extremely proud of his accomplishments, which can match or exceed any of us because he has beaten the odds.

Ryan's life now is individualized and he has a person-directed plan that has evolved over the years. His weekdays are spent in the community with a variety of meaningful activities which include volunteer job activities, socialization, physical exercise, continued learning opportunities and recreational experiences.

Three years ago, my husband and I decided to move forward with our plan to build a house with a section that would be Ryan's, to give him pride of ownership of his living environment and to ensure that in the future he would have the foundation in place to maintain choice and control of where he lived.

Ryan requires 24-hour support. He has medical, physical and personal care needs. As a family, we are continually planning and trying to do our part to make sure that Ryan has a safe and secure future.

Most of us take for granted being able to direct our own life, make choices in all areas of our life and have support from people who love and care about us.

The institutions for the developmentally disabled have closed, but there is still that ominous cloud hanging over their lives. Individuals and families have been reduced to begging for support desperately required to live a life of freedom and choice. The transformation that is occurring is a contradiction to the key elements of true citizenship rights.

I have a few other comments that I think are important:

(1) Individuals with developmental disabilities live below the poverty line, and ODSF is not adequate to cover food, shelter and clothing. It is unrealistic to consider using any of this money for support requirements.

(2) Families who have their children at home provide a large percentage of natural support. Illness and the natural aging process create the inevitable need for additional support.

(3) Since the implementation of the Passport Program funding in 2006-07, there have been no cost-of-living increases and no apparent mechanism in place to enable increases. If and when agencies receive base budget increases, the increase would not appear to apply to Passport funding and individuals who utilized direct funding dollars.

(4) The proposed changes in Passport funding guidelines last year appear to be restrictive and inhibit freedom of choice.

(5) The ministry promotes the use of the American Association on Intellectual and Developmental Disabilities—AAIDD—supports intensity scale, SIS, to determine levels of support needs. In the USA, there are four funding levels with annualized funding allotments exceeding \$100,000 for support needs, depending on the individual's specific needs.

This is the manual. I don't know if everybody's seen that. I have it in my presentation—a copy of the first page and where to find it.

In Ontario, there are waiting lists for assessments and excessive waiting lists for funding. The maximum funding available through the Passport Program is well below the annualized funding dollar amounts used in the USA relating to the SIS. It appears that the ministry is using a tool to measure needs but not following through with the purpose and intent of the process; that is, to determine the amount of funding that an individual would require to have a good quality of life. The maximum amount of funding available through the Passport Program is excessively below the annualized funding dollar amount in the US.

(6) The current situation in our province does not reflect meaningful quality of life. The same organization, AAIDD, has a statement as to what points they believe are important in quality of life, which I've included in my presentation. Although the SIS is utilized here, it is not creating the characteristics of quality of life.

(7) "The Natural Authority of Families," Michael Kendrick, point number four, which I've included: "Families have a stake in outcomes. For example, they have to live with the long-term consequences of service failures to a greater extent than any other party, except the person themselves." Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you very much for being here this morning and for sharing the story of Ryan with us and for your recommendations.

I will turn it over to Ms. Jones or Ms. Elliott—for the sake of time, just for a comment.

Mrs. Christine Elliott: Sure. Thank you very much, Ms. Rivington, for being here today. You've raised a number of points that have been raised by many other presenters. I'm just very glad that you were able to find some resources and supports to create a meaningful life for your son.

My question really relates to the individualized planning and how you were able to do that. Was that just something that you and your family did on your own, or did you receive any outside assistance in order to do that?

Ms. Joyce Rivington: Mainly because there has not been a lot of support for the type of life I wanted my child to have. I know a lot of families and organizations across the province. Somehow or other, years ago, we all connected. A Windsor organization has been very instrumental—I know parents from there. I knew parents in

Toronto who were forerunners in this type of movement—John Lord.

So I compiled all the information and I made a proposal, and I just persisted. Persistence and determination is what it is, and it takes a lot of energy, but it was my child. I mean, we do spend a lot of time and energy on our normal children, and I've had to spend a lot of time, but it has been a learning process. I didn't look at it, or teach my other children to think of it, as negative. At some time in all our lives, we need help and support. It has paid off.

1040

Mrs. Christine Elliott: That's wonderful to hear. But it is so draining for many families, just in the day-to-day care of their son or daughter, that it's really hard to be able to pull those resources together by yourself. We have really looked at the concept of a navigator, having someone to help parents plan for their child's lives and to even inform them about what services and supports are helpful.

Thank you very much for presenting to us today. That's very helpful.

Ms. Joyce Rivington: Thank you.

The Chair (Mrs. Laura Albanese): One second; we have comments from each party.

Ms. Joyce Rivington: Oh, sorry.

Ms. Cheri DiNovo: Thank you so much for this presentation and for introducing us to and supplying the supports intensity scale as well; that's helpful.

It strikes me that a lot of what is being experienced is people being assessed and the point of assessment is lost.

Ms. Joyce Rivington: Yes.

Ms. Cheri DiNovo: The point of assessment is so that you get some assistance and the assistance matches the need, but that's the part we're not seeing. So you've made that very clear, and I thank you for that.

The \$100,000 mark that you talked about in the American assessment model pales in comparison to what we're paying out for long-term care and hospital beds. These are inappropriate places where folk with developmental disabilities are being housed, and they're costing a whole lot more than the money that perhaps you might get, or families might get, if the assessments were actually followed through on. So thank you very much.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair. Thank you, Ms. Rivington, for being here today, for sharing Ryan's story, and for all that you have done to provide that loving home for him.

What I appreciated about your presentation was that you guided us to where there were things that were working right within the system, such as your experience with the regional office in Kingston and the support that was provided, and where you believe that there needs to be improvement.

In addition, you've also given us some very valuable comparative data as well, such as the supports intensity scale.

I want to thank you for the thoughtfulness that you've put into this presentation, and it's very helpful to us.

Ms. Joyce Rivington: Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you once again.

MS. IMAN SEIFELDIN

The Chair (Mrs. Laura Albanese): We'll now move on to the next presenter, Iman Seifeldin. I hope I pronounced that correctly. I'm probably totally off.

Good morning. How are you?

Ms. Iman Seifeldin: Fine, thank you.

The Chair (Mrs. Laura Albanese): Thank you for being here today.

Ms. Iman Seifeldin: My name is Iman Seifeldin. I came here today to talk to you about my son, Karim.

My son has a complex disability: cerebral palsy, spastic quadriplegia, severe developmental delay, autism spectrum disorder, scoliosis, severe communication disorder, pica-like behaviour, and aggressive and self-abusive behaviour.

Karim is 21 years old and completed school in the summer of 2013. It was a great experience, being in the DH classes, the developmentally handicapped classes, in the school system.

He has lived at Welcome Home group home in Ottawa since he was 11 years old. I have a very good relationship with staff and the director, Mr. Pelletier. I am a single parent and have had serious health issues, so I physically was unable to care for Karim at home, and I was faced with no other option but to place him in a group home.

They say I am a good mother, and I am very involved in my son's life. I love my son dearly. I have always attended his school meetings, home meetings and medical meetings, to make sure that everyone understood Karim's needs. He has problems keeping weight on and is extremely thin, so I make him special meals to encourage him to eat. I also hire a support worker, who helps me take Karim out on the weekends.

I have lived in a state of anxiety and fear for Karim's future for many months now. Karim does not have stable funding for a day program, and the group home where he lives cannot keep him on a permanent basis if he does not have a day program because it does not have adequate funding to support Karim during the day. The group home offered to provide a day program if the ministry would give them additional funding. The group home, however, did feel it was in Karim's best interests to have day activities outside the group home.

I thought we had everything in place for Karim's transition from school. The school had been on board to make sure Karim had a smooth transition. An assessment had been completed by the DSO, and the report identified the importance of transition planning. A day program, ICSS, had provided a proposal for the cost of a day program for Karim and had visited Karim twice when he was still in school. Karim had good support for his transition, and the only thing missing was that there was

no stable funding being made available by the Ministry of Community and Social Services for Karim to have the long-term security of a day program.

Without secure funding, Karim's group home placement is at risk. All that is in place are short-term solutions. There is funding until the end of March 2014, but then what will happen to Karim?

I am constantly in a state of worry and fear. I thought we were being proactive in planning for Karim's future when we looked into day programs well in advance of him leaving school. Now I feel that planning for Karim to have stability in his life in the future is at risk.

I also feel that the system is very disjointed and confusing. Karim has a case manager at Service Coordination. There is another individual at the DSO, but he was not the same person who did the assessment on Karim. Then there was another committee, the adult service resolution process, which considers people who are priorities for funding at the service providers' table. For some reason, even though Karim was leaving school, his file had been closed, and he was not prioritized to the level required for funding.

Karim's worker from Service Coordination knew in April 2013 that Karim could be discharged from the group home if he did not receive funding. The group home had to put in writing to Service Coordination that it would not provide support to Karim during the day even though the group home only received funding for residential accommodation for Karim.

All of this confusion has been going on since April 2013. It is my child's life, and people don't seem to understand.

I was told by the adult service resolution person that she did not want to know my son's name because he would be identified by a number. She gave me still another name of a person who I should be dealing with at Service Coordination.

I feel like my son is not even a person. His future is uncertain. There are so many layers of bureaucracy and a lot of confusion and time wasted, making families feel frantic and like they are going around in circles.

What will happen to my son if he does not receive funding for a day program? Could he end up in a nursing home? I am so very frightened and worried for Karim's future.

I am thankful that I heard about this committee, and I want to thank everyone on the committee for giving parents like myself the opportunity to speak about the concerns we have for our children and their futures.

I am including some correspondence with my written submission. I'm sorry it's quite a bit, but we're just trying to give you an overview of some of the communication that has been going on and the new processes that have been put in place. Nothing came out of the resolution processes because we ended up having the same term, which is, "No funding; the government is not injecting any more money in the process." I was told that we have to wait for somebody to die to have money in the system to support people like my son. Thank you.

1050

The Chair (Mrs. Laura Albanese): Thank you, first of all, for sharing your emotions and your uncertainty with us, which is perfectly legitimate. I will turn it to my colleagues to make their comments and ask you their questions. We do have about three minutes for each party. Miss Taylor, you can start.

Miss Monique Taylor: Thank you, Iman, for coming to speak with us today and sharing your story and Karim's story with us. It's not the first time we've heard that people who are living in group homes are not getting the day programs that they need, and it's so unfortunate. It's like, because you have the group home, you're automatically privileged and you don't get to be on the list for the other day programs that are so necessary.

I mean, the group home is a place to sleep and to be cared for in your daily living; it's not about the quality of life, of getting out into the day programs and those other vital services that are so necessary. So thank you again for raising that attention that we have discussed and finding that that's a problem.

I also wanted to know your thoughts on the DSO and the services that you've been provided with that.

Ms. Iman Seifeldin: The first assessment I had—actually, it is attached to the SIS assessment. The ADSS assessment was done by a lady by the name of Heather Williams. We had two meetings with her. It is a very comprehensive assessment. It does cover what my son needs and it has been identified clearly, which is great. It did identify that he is going to need day activity when he graduates at 21, but nothing was done with that. We had to wait again and do an update when we were really in crisis at the time that he was just graduating. The assessment was done in February 2011 and he was graduating in 2013, and nothing was done with the assessment. Service Coordination did not even have a copy of the assessment, and I provided my copy to them.

Miss Monique Taylor: Right. We know that assessments are very, very expensive to be done, and to be done when they're not even being used is really a shame. I really want to thank you for providing us with correspondence. This puts us into your life in a very delicate way. I appreciate you taking the time to do that and allowing us to see that correspondence and the dialogue that's happening between yourself and the services that are being provided to your family. Thank you once again.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter?

Ms. Mitzie Hunter: Thank you, Ms. Seifeldin, for your presentation and for sharing your journey so far with Karim, and also for providing the detailed assessment. I agree with you that it was a very good assessment and it clearly outlined what the needs are. It seems like we're hearing again that where the gap is is matching those identified needs with the resources and the supports within the community for you.

The information that you provided to the committee is what we are considering in terms of, how do we improve the system of supports? Clearly, your son has multiple

diagnoses and requires that level of support. How do we work together as a system so that all ministries are working together in a coordinated fashion so that you don't experience the level of uncertainty that you have right now?

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Soo Wong: Thank you very much for your presentation. I want to ask two quick questions. First I want to hear your comments, specifically when the agency asked you not to name your son—instead, the numbering. Can you elaborate a little bit further to the committee?

Ms. Iman Seifeldin: The process for prioritization: They take away the information about it and they are represented without their information—what's the name and what's the group home he's in. All the information is blacked out when they are presented to the table for prioritization, which really does not make much sense to me because they are persons. They have rights. I do not have a problem with my son's name being mentioned in any service that he'll be getting.

Ms. Soo Wong: You have expressed concern to the committee with respect to the nutritional concerns. Was there any follow-up from either the Ministry of Health through your physician, or—

Ms. Iman Seifeldin: Yes. Oh, yes. He had another problem with the system—that when he was in school, he had a dietician as part of his health team. He had a physiotherapist, a speech therapist, an OT who would look after him and give us recommendations. We are following until now the recommendations of the dietician that have been recorded, and there has been a lot of information about his diet coming from his dietician, which we lose. Once you're 21, you lose these services and they don't come automatically. You have to reapply. And you hardly can see them, once a year if you can—while they were available in the school system and OHIP was paying for them. What is the difference when you change and be 21? Why is that taken away from you? You are still the same person with the same disability. Reaching 21 should not have any difference, because for this group, they are the same people, whether they are 21 or a teen. They still have disabilities that take them to a toddler or even a younger person. So at 21, we should not punish them for turning 21.

Ms. Soo Wong: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Mr. MacLaren.

Mr. Jack MacLaren: Ms. Seifeldin, I see you live in Kanata, which is my riding, so I am your MPP.

Ms. Iman Seifeldin: I actually don't live in Kanata.

Mr. Jack MacLaren: Oh. I see your address is here. That's Kanata.

Ms. Iman Seifeldin: Oh, no.

Mr. Jack MacLaren: At any rate, what I was going to say is that perhaps one of us—I would offer to try to help you. It seems like what you need immediately is to get funding so that your son can continue to stay in the group home that he's in, which seems to be quite satisfactory.

Ms. Iman Seifeldin: Yes.

Mr. Jack MacLaren: And what's unsatisfactory is that funding is not there, so I'd be happy to try to help you with that, so perhaps we could meet after this meeting and we can set up a meeting with you at my office, if you would like.

Ms. Iman Seifeldin: Yes, I would appreciate that.

Mr. Jack MacLaren: And we'll look into the problem. I know all these good folks, so I've got some good friends to ask for help, and we'll do the best we can to help you.

Ms. Iman Seifeldin: Thank you.

Mr. Jack MacLaren: Okay.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation this morning.

Our next presenter has actually cancelled. The 11 o'clock will not be able to make it.

We will call the following presenter up, the Queen's University Department of Psychiatry.

Yes, Ms. Wong?

Ms. Soo Wong: Madam Chair, while we wait for the next witness to speak, can I ask—

The Chair (Mrs. Laura Albanese): Make your way as Ms. Wong is speaking.

Ms. Soo Wong: —the researcher to follow up on a couple of things for me? First, the witness from the MAPS people, their study—because I have some more questions, so I'm going to give them to Erica so that she can follow up to the committee for me, because with regard to some of the data, I want some more data.

The last witness shared with the committee—I want some more clarification from the Ministry of Health and Long-Term Care with respect to special diet funding for those over 21, so someone with a diagnosis of DD or ID and with a medical order that the person has special diet needs. So my question is, how does the Ministry of Health and Long-Term Care fund special diets for those with these kinds of medical conditions and why is there “discrimination” because of the age?

1100

Then the other question here is with respect—

Ms. Erica Simmons: Sorry. What was the last—

Ms. Soo Wong: Discrimination over the age group. Because that particular witness said her son got all this medical dietary support prior to 21. We know the Ministry of Health does fund nutritional—

The Chair (Mrs. Laura Albanese): But they've changed some of the rules, so it could be because of the change in the rules.

Ms. Soo Wong: Yes. I don't know.

And then the other question, Madam Chair, is the process where the committee, which I think was the assessment committee—that instead of naming her child, there is a number. Can we get the protocol or procedure when they go before the committee? Is it a requirement that they do not disclose the name of the individual? Is that part of the Integrity Commissioner or the privacy act? I don't know. But why isn't it allowed to be shared with the committee when they are discussing the client?

The Chair (Mrs. Laura Albanese): The researcher would like to know also the details of what you require in regard to MAPS.

Ms. Soo Wong: I will give that to her at lunch.

Ms. Erica Simmons: Okay. Thank you.

DEPARTMENT OF PSYCHIATRY, QUEEN'S UNIVERSITY

The Chair (Mrs. Laura Albanese): Okay. Thank you for waiting patiently for a second here. Please introduce yourselves as soon as you make yourselves comfortable. You may start any time. You will have up to 20 minutes for your presentation.

Dr. Bruce McCreary: Good morning and thank you for making a spot for us today. I'm Bruce McCreary. I'm emeritus professor of psychiatry at Queen's. On my left is Dr. Jessica Jones, who is an associate professor of psychiatry. She's a clinical and forensic psychologist. I'll mention that perhaps a little later in relation to some of the complex cases we deal with who happen to be in conflict with the law. On my right is Dr. Muhammad Ayub, who has been with us for a few months, having trained, as did Dr. Jones, and me a little bit, in England. We have recruited him—some would say seduced him—to come to Canada to help us out with what I'll describe in a minute as a very distinct manpower shortage in the field of mental health professionals serving people with developmental disabilities and dual diagnosis.

As the senior citizen in the group, I can tell you that what you're doing was last done, as far as I know, in 1971 by Walter Williston, who was engaged by the Ontario government to review the care of people with developmental disabilities in Ontario and to develop a report with recommendations. I remember meeting Mr. Williston, and I want to make one quotation from his report, because it has to do with how things have evolved in Ontario since 1971, and in that sense it's important to understand that evolution in relation to the challenges we face today.

The quotation is, “The concept I strongly advocate is that it is far more economical and humanitarian to give to the handicapped the total care he needs in his own community than by providing for it in an institution.”

The impact, really, of the Williston report and the events that followed can be categorized into three: de-institutionalization—and as you know now, by March 2009, all of Ontario's institutions were closed; social inclusion, which is the focus of current policy; and the third thing, which in fact we're in a way going to focus on, integration of people with developmental disabilities in mainstream health care services.

Presently, I think you might agree, care in the community is not more economical; it's more expensive. Quite frankly, if you haven't spent, as a government, enough money on it, you can explain at least some of the challenges you're hearing about.

Secondly, there are significant gaps in the provision of community supports for individuals and families. I know

from the transcripts that you're hearing that message over and over and over.

You may not have got quite as clear a picture of the third point, that there's unacceptable neglect of the special health and mental health problems to which persons with developmental disabilities are predisposed. I know you've highlighted dual diagnosis; in fact, dual diagnosis affects 40% of people with intellectual disabilities, a factor three or four times the rate that occurs in the rest of the population.

Some of the challenges, I think, are reasonably clear. I think the historic perspective is interesting because some recommendations are needed now to sort of redirect the way things have evolved since 1971. We have a suggestion to make today in terms of perhaps shifting the direction a little bit.

The suggestion is this: to engage Ontario's six academic health science centres in reversing contemporary neglect of the health and mental health problems of persons with disabilities. I'll try and explain a little bit why we need to do a better job. Essentially, if you're going to integrate people with disabilities in mainstream health care services, and if the staff in that mainstream are not adequately trained about the special needs of people with intellectual disabilities and dual diagnosis, we clearly have a problem, and the problem is, in many senses, in the first instance, educational.

An academic health science centre, just so we're all on the same page, is a post-secondary institution training physicians and nurses and rehabilitation therapists and dentists and pharmacists in collaboration with what used to be called teaching hospitals. It still is teaching hospitals, but it goes beyond that, particularly perhaps in relation to this population, to other agencies in the community that serve people with intellectual disabilities and dual diagnosis.

This slide shows you a list of some of the agencies that our division relates to in southeastern Ontario. Why we relate to them is that they expect from the academic health science centre specialists help in caring with people with complex needs. That help sometimes is direct and very often is indirect in the sense that we're dealing with professionals who didn't have adequate training in this field, so the consultation is really to provide direct help but also some further education for the practitioner who was shortchanged during their training. The services, really, then of an academic unit are specialized care, training of health care professionals and what you heard from Hélène and her colleague in terms of research.

Our former vice-principal used to say it's a three-legged stool, and if one leg is missing or short or whatever, it doesn't work optimally for anybody. If they all are in place and work together effectively, it's win-win. That's not a political statement because he made it before the current Premier was identified.

We're in Ottawa, and if you go over to Carling Avenue and drive down there, you'll see the highly respected—and it is respected—cardiac institute, the

Heart Institute. If you continue your drive around Ottawa, you will find nothing, in terms of intellectual disability or dual diagnosis, that's comparable.

1110

Just to put that in a bit of context, this is a cost-of-illness study report from the Netherlands. In fact, it's the only one I know where a jurisdiction has said, "What do we spend on cancer? What do we spend on congenital anomalies? What do we spend on intellectual disabilities?" etc.

At the top of the list—and it's there in green—the most expensive diagnostic group is intellectual disabilities. It's more expensive than heart disease. It's more expensive than cancer. To think of the emphasis placed on other conditions—we don't deny those other categories the respect they deserve, but to neglect this population is not right. It's not fair.

The academic health science centres, in our view, need to be harnessed, because we know that people in training are shortchanged in terms of education about these matters. In fact, we know we don't have enough clinical educators with the specialty knowledge that Dr. Jones and Dr. Ayub bring in from Britain so that we can keep our program at Queen's going.

So this is a long-term suggestion in the sense that if you said today to the six academic health science centres, "Set up a special program in relation to intellectual disabilities," it would likely take them two or three years to set up, in terms of including recruiting people with the necessary expertise, because we haven't trained them, quite frankly. But we have to start, and the sooner we start, the better.

Finally, in terms of a concluding comment, it seems to me that if the policy is, and is going to continue to be, integration of the people we're talking about in mainstream services, we simply have to train the people to look after them. If we don't, we're shortchanging them—seriously. There's data in many jurisdictions about premature mortality, not to mention all the enhanced daily problems and disability experienced from illnesses that they are predisposed to that are undertreated.

I hope we have some time for questions and comments, because we didn't want to give you a belaboured presentation, and we want to make sure you have a chance, if there are puzzles in what we're suggesting.

The Chair (Mrs. Laura Albanese): Yes, we can. There is some time left over for questions and comments. It will start with the government side: Ms. Wong.

Ms. Soo Wong: Thank you very much, Dr. McCreary, for your presentation. Your colleague from another department presented to us just recently. What's the collaboration between your department and her presentation with respect to the data for MAPS, and how does that support in terms of solutions and policy improvement? So what is her research in MAPS, and what is your department doing, in terms of interdepartmental collaboration?

Dr. Bruce McCreary: The three-legged stool I mentioned: service, training, research. An academic unit, like the division we're from, has the three functions.

It so happens that the people who are working on the MAPS project—Hélène Ouellette-Kuntz, whose office is literally across the hall from mine, is focused on research. She doesn't provide specialized care; she provides some training to epidemiologists in training. She's an important member of our team, but so is a clinical psychologist, and so are psychiatrists, and so are primary care physicians, and so are occupational therapists and social workers. So this is inherently an interdisciplinary effort. When you ask an academic health science centre to address the problems in the field, you're trying to buy a package with three legs. That's the connection.

Ms. Soo Wong: We heard earlier from parents, not just in Ottawa but across the province, that there's poor coordination and communication. We look to experts like yourself in the academic community to share with us how much collaboration and communication between the department of psychiatry and your colleagues with the faculty of education—because we know these young people with DD and ID are in our classrooms. We consistently heard that educators and health professionals are not properly trained, so I need to hear from you. Are you collaborating with your colleagues in different faculties and different disciplines?

Dr. Bruce McCreary: I think the answer is yes, but I'm going to answer it quickly and then perhaps the others will comment as well. We have included in our handouts a booklet that Dr. Jones and I have just published on how to train health care professionals, and it includes how to relate to teachers, to caregivers who are family members, to caregivers who are agency staff and so on.

In the tool kit of a well-trained physician or nurse or social worker or OT is the ability to coordinate at a local level so that the package that a family receives hangs together as distinct from what they often report now, where there is no communication. If you don't train your providers on how to communicate effectively with other disciplines, it's, again, not too surprising they don't do it very well.

Dr. Muhammad Ayub: And I'd like to answer that question. I'll give you a comparison: The last organization I worked for, in England—they are called health trusts. It was a mental health and learning disability—which is equivalent to intellectual disability—trust which provided service to about 1.4 million people in northeast England. Just that trust had between 25 to 30 consultant psychiatrists who were dedicated to intellectual disabilities.

When Bruce McCreary and Jessica Jones interviewed me for my job, they were very clever, actually. They didn't let me know that there is no dedicated intellectual disability training in Ontario or in Canada. I thought that it'll be a service for a small population, because just one psychiatrist can't do that. I realized that it's about a half-a-million population which I'm expected to serve, with no interdisciplinary support, apart from one psychologist. So how many jobs can one person do? I think the problem is what Dr. McCreary has already suggested:

that you don't have enough people on the ground to coordinate. If you don't have the nucleus that can coordinate different bits after service, then it doesn't happen.

I only arrived in May, and the place where I worked for a 1.4-million population had more than 100 dedicated beds for intellectual disabilities, patients with psychiatric problems. There were none in the region of half a million. I managed to get two; now, I have to look after those two in-patients. I have to provide care to everybody living in the community with intellectual disabilities and psychiatric problems. I have to teach undergraduate medical students. I have to teach postgraduate trainees. You can't expect that to happen.

The problem is not that there is no will, that there is no motivation; the problem is that there is no manpower. Unless you address that issue, you are likely to continue with these problems in the next 10 or 20 years.

1120

For comparison, I'll explain what training I had. After five years' training in psychiatry, I had three years' dedicated training in intellectual disability psychiatry to qualify to become an intellectual disability psychiatrist. How long do my colleagues in Ontario have for intellectual disability? Zero; they don't need to have a single day's exposure—maybe a week actually. We run a crash course for five days to cover what I covered in three years. They must be very bright and somehow exceptional to acquire the same skills. When I see patients—I'm not intending to criticize anybody—I see glaring gaps in terms of diagnoses, in terms of treatment they receive because people haven't been trained; they haven't been exposed.

The problem Ontario is having now, Britain had it about two decades ago. They started closing their institutions a couple of decades ahead of you. At the time they thought, "We closed the institutions; the problem is solved. We don't need specialist services." They have come full circle, actually. You need a core of specialist services to look after the most difficult and most complex people. That core specialist service supports the other services. Unless you have that core, your other services are orphaned. They can't survive. I have seen my general psychiatry colleagues; they so much appreciate just my presence so that they can ring me and seek advice about one of their patients. When they are in a difficult situation, they can ask me to have a look at one of their patients.

I think you're lucky that you had Dr. McCreary, who had an interest. He went to England to acquire some special training. A few decades ago, he established that division. Otherwise, it would have been non-existent. There are only two academic health science centres that have those divisions. One of them is just because of Dr. McCreary's own personal sustained effort.

I think that's the answer: You need to have a core to coordinate training and to coordinate care.

The Chair (Mrs. Laura Albanese): Thank you. Now, I just wanted to have a word with the other two parties on the committee. Obviously, this answer has gone over the time that we had at our disposal—

Dr. Muhammad Ayub: Oh, I'm sorry.

The Chair (Mrs. Laura Albanese): But at the same time, because we had one of the presenters cancel, do you agree that we can use this extra time for further questions? Is that okay? Okay. Ms. Elliott.

Mrs. Christine Elliott: Dr. McCreary, Dr. Jones and Dr. Ayub, thank you so much for being here today. I think you've brought a critically important perspective to us. We have heard, as you mentioned earlier, Dr. McCreary, about people with intellectual disabilities and with dual diagnosis not receiving appropriate primary health care as well as care for their particular situation in the province of Ontario. I appreciate your suggestion; I think that's really important in order to be able to train health care professionals, whether they be family physicians or whether they intend to become specialists.

One of the other issues that has been brought to us is the fact that, like psychiatry—I think this is similar with developmental pediatricians: It's not something that's seen as being a very sexy thing to do in terms of medicine, that there are other specialties that are seen as being more important. Quite the contrary. I agree with you. But I guess one of the things is getting to medical students and getting them to see this as being a pathway for them that is going to be both personally meaningful and remunerative.

I understand that the medical students group have a list that they're now thinking of posting, a registry of where there are openings. Certainly, there's no question there's an opening in this area. Hopefully that will help entice young people to become interested in becoming developmental pediatricians. That's just a comment. The other is a question: When people do go into these specialties, how do we remunerate them appropriately so that they can take the time that they need in order to give good, quality care to people with intellectual disabilities or with dual diagnoses—because sometimes they feel reluctant maybe to take them on because of that additional time? I'd appreciate your comment on that.

Dr. Jessica Jones: May I speak to that?

Dr. Bruce McCreary: Sure. I'll let Jessica speak to it in a moment because, as you may know, as physicians we can at least bill OHIP for services. It takes longer than the OHIP fee schedule accommodates to serve people with complex needs. But a bigger problem is clinical psychology, social work and OT, which don't have a mechanism to charge their services like OHIP. Jessica can—

Dr. Jessica Jones: As Dr. McCreary said, I trained both in Canada and in the UK so I've had the comparison of both. I think after working 10 years in the UK and coming back here, capacity building, as he speaks to, is essential, but it's about timing of training.

In the UK at the point of graduation, no matter what specialty you go into, all psychiatrists, psychologists and nurses have done a mandatory rotation in developmental disabilities or learning disabilities irrespective of what specialty they go into. For me that accomplishes two goals. One, we're attracting them early on in terms of exposure and garnering interest in the field, if we're

lucky, but also tackling some of those stereotypes and misguided assumptions about this population. I find in Canada we're playing catch-up and that we're trying to educate experienced professionals—already confident clinicians that may not be open to learning at that point. It's a challenge—and that's the physicians as well as all other professionals. For me, at Queen's, we're trying to do it one student at a time, but it's a drop in the bucket. So trying to get them early on is very important because it also tackles those societal norms that you heard out loud on your first day in terms of how do we do that.

Secondly, the funding mechanisms: I can say from my clinical experience here, responses are being left to government funding programs—so we think about medication, which you've heard about because it's funded through the physicians, as well as the criminal justice system, unfortunately, because they can't say no.

So, yes, capacity building in terms of professional supports as well as the whole funding mechanism for non-physicians or allied health professionals is a huge crisis.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you, Doctors—a wonderful presentation and absolutely necessary, so I thank you for that and I thank you for the book.

We have heard across Ontario, as you have read, probably, if you follow the transcripts at all, about the lack of diagnostic centres and the lack of ability to find any treatment whatsoever in some communities. We just came from Moose Factory where it's isolated communities and many First Nations communities can't get to a centre at all. One of the thoughts that came up was of satellite centres that would at least provide the minimal diagnostic abilities. I know your background is in part in forensics. You're absolutely right. We heard about a study in Alberta. Some 60% of inmates in the penal institutions there are thought to have FASD. Again, how do you get a diagnosis of FASD if there's no centre anywhere near you that can give it? I'm wondering if you could comment on this idea of perhaps—I mean, we have big centres now but you have to get to them and there are huge waiting lists. What about more mobile-specific satellite centres? Is that a possibility, do you think?

Dr. Jessica Jones: I think it is. It's about manpower and about attracting interest early on in health care students and professionals, because for the lack of having DD-dedicated programs we have to infiltrate to normal curriculums—so garnering interest again at a level when students are still figuring out what specialty they need to go into.

Dr. Muhammad Ayub: We already do clinics in Belleville and Brockville. I'm planning to start one in Peterborough. I think we are trying within our capacity, but how thin can you spread a small number of people? Unless you have those centres, you can't mend—a parallel is the World Health Organization trying to integrate mental health in primary care in the world. It has never worked because you need to have the centre that trains specialists, and then—you can't bypass this

training and having skilled professionals. You can't have any—but, yes, your question about remuneration: I think if you have dedicated positions for intellectual disability, psychiatry and psychology, that would create a chain where people from training have the prospect to move into those positions. So now anybody can apply for a position or anybody is expected to serve intellectual disabilities—which is fine for the majority of clients. But if you have dedicated positions or intellectual disability experts, that would create a bigger attraction for people to go through the training, so that they can see a clear path.

1130

Dr. Bruce McCreary: Could I comment? Words sometimes are important. In fact, I've used the term throughout today "academic health science centre," which means something to many people in Kingston. But in fact, the newer term being developed to substitute is "academic health networks," and Queen's I think is an example of that. We have a growing medical school and a fixed population base, so we now have satellite training centres. I think the idea of a network encompasses that. So you can find a head office in Queen's, but you can find a training package in Oshawa or Peterborough, and in the case of Western, down in Windsor and so on.

So I don't think we should get too focused on "centre," if it means it's all concentrated in one city and everybody in the region has to travel there. That's not, particularly with this population, a particularly feasible enterprise.

Ms. Cheri DiNovo: It clearly depends on the people first.

Dr. Jessica Jones: Absolutely.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Thank you for your most interesting presentation. If members still have questions, perhaps they can address the presenters offline. Thank you again.

PEOPLE FIRST OF ONTARIO

The Chair (Mrs. Laura Albanese): I am going to call the next presenters up, People First of Ontario. Good morning and welcome. How are you today?

Mr. Kory Earle: I'm good, and how are you?

The Chair (Mrs. Laura Albanese): We're good. Thank you. You'll have up to 20 minutes for your presentation. I see we have a copy of it, and you may begin at any time.

Mr. Kory Earle: Perfect. Just a warning to Jack: Don't ask me any tough questions just because you're from this area.

Good morning, and thank you for allowing me to have the opportunity to speak on behalf of People First of Ontario today. I will address some of the concerns our members and others face in this province. I must say, since I've indicated coming to the select committee, a lot of responses have gone on with regard to direct funding. So although direct funding is not in your presentation, it

is something I will briefly hit on, as most of our members are certainly facing it today, and also the need for supports, not just through agencies—but for people to hire their own support workers, which in fact does save the government money, so people can have support at home. We hope at the end of this meeting that we'll continue to work together, ensuring that the most vulnerable people's voices are heard.

Let me first talk about who we are. Our goals are to promote equality for all citizens; to assist other people trying to speak up for themselves and make their own decisions; and to teach our members about the rights, abilities and strengths of People First of Ontario.

Our driving force: We want people in the community to see us as people first. The problem is we are still being labelled with damaging words like "retarded" and "slow." We have been taken away from our families and communities and have been kept in institutional settings. We have been kept in segregated workshops and schools apart from the people in our community. People have forgotten that we have the same dreams and the same needs as everyone else, as they do.

The objectives of People First are:

- to promote equality for all persons who have experienced being labelled developmentally disabled;

- to assist each other in speaking up for ourselves and making our own decisions;

- to teach the community about the rights, abilities and strengths of people who have experienced the label of developmental disability;

- to hold meetings and discussions for the purpose of organizing and educating people with developmental disabilities;

- to increase the membership, help new chapters get started and provide continuing support in order to further these objects. I would be remiss if I didn't point out that Lanark county is here today. They're just outside of Ottawa. They're here as one of our local chapters in the province;

- to raise funds and acquire property for the purpose of People First.

I would now like to talk about a few areas that we are concerned about, which is no surprise: poverty.

Ontario Disability Support Program: We and our members are very concerned about ODSP being cut. Already, many of us cannot afford a good place to live, nutritious food, transportation and other basic necessities. Far too often, the disability sector is one of the first things cut, and we do not want it to be slashed. For many people on ODSP, it's their only source of income. We must start looking at the income that people get from ODSP and ensure that they are getting enough money to cover rent, utilities etc.

Far too often, people with disabilities are targeted first. The government can be a champion for making people with disabilities have and live a better life and not be living below the poverty level.

It is suggested that the Ontario Disability Support Program and Ontario Works will be combined together.

We believe ODSP and OW need to be separate. We understand that both entities are social services. If the government is considering doing this, and if this is to do some cuts by putting it like one stop, then the government must ensure that ODSP and OW remain different and that our members and the citizens know how it is changing. That's a huge concern that we get day in and day out from our office, about that happening.

Developmental Services Ontario: I will talk briefly about this and also talk briefly as a family member, someone with a twin who is experiencing the system right now, actually, as we're going through the process.

Assessments: I've heard right across this province that the supports intensity scale assessment that people have to go through before getting support or being put on a wait-list is something that breaches privacy and, in fact, only labels people more. Some people have had the SIS assessors at their home for six hours and more. Other barriers to access to supports include the requirement to have a psychological assessment, even when there has been a clear developmental diagnosis given medically.

I could go on and on about how we need to change the assessments. I hope that you, as a committee, will take action on changing the assessments and making sure that the individuals are dealt with in a respectful manner.

The time to get a meeting takes more than needed. My twin, who deserves a better life, should not have to wait long for the assessments. He received a letter in July 2013, and the meeting has been cancelled three or four times. We now have one on January 29, 2014. I marked down the dates, but I'm also prepared to cancel, just in case.

1140

Developmental Services Ontario must be the same right across this province. I question things like my twin getting denied for supports in Ottawa until mental health pointed out that he should have gone through the south-eastern and not the Ottawa region. When they put him in the southeastern region, he did get accepted for an assessment. In fact, it said that he was grandfathered—but denied in Ottawa. I take that with very much concern, and I think this shows a lack of information that's going on right across this province. If it's going to happen in Ottawa, if it's going to happen in different—I can tell you, it's happened in different areas. Talk to members of our organization in London. They will tell you first-hand. Again, I ask that you recognize that this needs to be changed and it has to be the same right across this province.

Wait-lists: With over 9,000 Ontario citizens with disabilities who are on a wait-list for supports, the government must act to resolve this issue. People's lives are at stake. People need support, and without immediate and appropriate intervention, we know that people will be hurt and some will die. The wait-lists will grow. We have enough challenges. We don't need our government or this committee to turn away. We are in crisis in this province, and I hurt for many that don't have someone to support them in their own community.

Hiring a support worker: When the new act was brought into force, it was supposed to ensure that people

could hire their own support worker. We have heard that the reason this has not happened yet is because there is no new money, although if there is no new money, I question why it was even an act, if it was going to give choice and equal opportunity.

My twin, who was through an agency three or four years ago, only spent an hour a week with them, and he was schizophrenic and then diagnosed with a developmental disability, so a dual diagnosis. I can tell you right now that he would rather hire his own support worker that he can trust and where he can be the employer, which has a huge impact on people being able to have that control over their lives. We're hopeful that this will be available in the coming days. By hiring our own support workers, it gives us power to make decisions about who comes into our homes and our lives. I know many people would benefit from this, and in fact it would give people choice. As well, people hiring their own support workers may actually save the government money. It is our hope that you, the committee, will take action on this issue.

Let's be clear that the Ontario Disability Support Program that many get to survive should not be used to hire support workers. I had so many calls yesterday about that. I'm telling you right now, if that's the case, you can be guaranteed we'll be the first organization up here battling against that. Our members do not want that. It's bad enough people are below the poverty line. We don't need governments dictating decisions by our members and by many people who face challenges. Let them have a life that they fully deserve.

Another issue is picketing in front of people's homes. We spoke out against this over the years. As you know, many agencies are funded by the Ministry of Community and Social Services. When there is labour unrest or a strike happens, the workers should not be allowed to picket in front of people's homes, as their safety, their privacy and their security are at stake. We have tried to bring the bills forward to deal with this important issue. We have nothing against unions or the employers. We want people to not have to worry if a strike happens. There have been recent strikes, one in 2007 and one in 2009, where people have lived in fear of picketing workers outside their homes. I have met many people living in group homes and I cannot put into words how scared and betrayed people feel. I hope this committee will support us in making picketing in front of people's homes illegal, as we fear that many more strikes could happen in the near future. We must put an end to that. We say that we need the trust of workers, but we must make it clear—and I think that's why my twin has turned off to hiring his own support worker, because he knows they will not strike.

Jobs: People with disabilities really want to work. It is shameful that only 25.9% of employers hire people with disabilities in Canada. We and others want jobs that pay real wages. This is something that this committee can push. Jobs must be something that people can and want to do—not have it decided for them.

Inclusive education: We need a better system when it comes to inclusive education. People should be in regular schools and classrooms, and when they graduate, they can feel proud. We must start looking at colleges and ensuring that when people with disabilities apply and only have a certificate from high school, the college or university must accept it.

Ontario is one of the worst provinces when it comes down to inclusive education. That's a fact: Look at other provinces and territories across Canada. As an inclusive rep, I far too often know about that and hear many stories. I can tell you right now, when I was in Newfoundland a couple of years ago, when people stood up from Ontario, they said, "Don't feel proud of the province when it comes down to education," because we're behind when it comes down to inclusive education in this province.

I too often know about segregation; that's what I was put through when I was young. Everyone should be included in all aspects of school life and not separated or segregated from anyone.

Housing is a huge issue. No one should expect someone to find a place for \$700. The money that many of our members get on housing is not enough. People are having to bunk up with people that they don't even know. I encourage this committee to work with the housing study group in this province, which I am proud to say that I'm part of. I got confirmation that they're speaking on Monday. You'll have an opportunity to hear that.

Something that I'm proud to stand behind and recognize: not everybody supports the idea of group homes. As far as I'm concerned, they're a smaller version of institutions in this province. Group homes should not be the answer, in my view. People with disabilities deserve choice and independence. Group homes are not that; in fact, when they share a place, they don't get a choice in terms of who they share the place with in the group home. When they come and go in a group home, it's not home to them. That needs to be dealt with. An average of four and up people in a group home—I can tell you, if someone told me that I would have to be in a group home, boy oh boy, you'd better watch out.

When we talk about hiring support workers, they can do that when persons live independently in their home. Having to hire a support worker is not saying that you can't hire them 24/7; it still saves money at the end of the day. It shouldn't be a money factor, because people's lives are at stake. But I know the question raised every time is about money. People with disabilities did not decide the deficit in this province, nor should they be neglected by this province, and that is what is happening.

We must remember that not everyone has a family or someone to advocate on their behalf. We must work with all those who are affected and start hearing all those who have no one. My twin is lucky to have us, a family; however, many don't.

People First of Ontario wants to work with this committee, all parties and the government to change how things transpire moving forward. It is very important that

individuals are always at the forefront when decisions are being made. We are happy to work with this committee on many issues. Again, this is the beginning, and I hope that what our members bring forward to, and what I bring forward to—this committee will take into strong consideration, because people are dying by the moment.

I'm proud that this committee is structured, but I'm also concerned for many who don't have here—although I told our vice-president it felt very lonely, because I'm very lonely here in Ottawa today because I have nobody beside me, but that's okay because I can fight any battle all by myself. People's lives are at stake. We need to get this crisis under control.

1150

People with disabilities can be a champion for that if you work with them, not against them. Encourage them and support them; don't go against them and don't discourage them. Let them have the life that they deserve. Quit dictating what they need. Unless you're in their shoes, you don't know what they experience.

Thank you for allowing me to have the opportunity to speak here today—and to many people who are in the audience, our address will be on our website, People First of Ontario, next week, with our comments.

Briefly, direct funding: As I mentioned, people are losing direct funding. I got so many messages yesterday that I could share of many people that direct funding—people are scared about Passport; people are scared about direct funding. There's a huge concern, so I ask that you take that into consideration. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. We do have the possibility to make a comment. Mr. MacLaren.

Mr. Jack MacLaren: Kory, good to see you again. You are an exceptional person, as any of us who have had the good fortune to meet you in the past—and many of us have because you come to our doors, you knock on our doors, and we appreciate that very much. You are a born leader: You are president of People First of Ontario, you were president of People First of Lanark County, and I believe you're president or vice—

Mr. Kory Earle: First vice.

Mr. Jack MacLaren: —first vice of People First of Canada. So you do a lot of travelling, more than most of us, I'd expect. We see your face at Queen's Park, and you tell us you watch us on TV, so you smarten us up quite a bit, Kory.

Excellent presentation: You've highlighted all the points that are salient here, problems that need to be fixed. I'd like to thank you for that. The one about not allowing workers to strike in front of homes—you've talked to me about that personally before. We haven't heard anybody else this week anywhere speak of it; that's very important. We know we have labour negotiations coming up at the end of March with a number of unions, and that could potentially happen. I would say this group really has an obligation to make sure it does not happen, because we understand. You explained it clearly, and we get that. So thank you for that. I would say that's probably our most immediate goal right now, because March

31 is a date that's not going to go away, and that would be a terrifying, terrible thing if we allow those kinds of confrontations to happen, as they have before, eh?

I won't go over everything you said, because you've said it all well and we all hear you. I would say, summing it all up, that basically what we need here is a different attitude—a better attitude—as a society towards developmentally disabled people and families and caregivers and that it's a desperate situation and that basically, as a society, as the people of Ontario, as the government, we have not done a very good job with it. I think probably summing that up, it would be fair to say that, as a caring society, we have a moral obligation to help people who can't help themselves. We are all here to do just that, Kory. I think you know that, and we know you're watching, so we'll do the best we can.

Mr. Kory Earle: Thank you.

Mr. Jack MacLaren: So do you have any comment on any of that, Kory?

Mr. Kory Earle: I do want to, first of all, thank you, Ms. Elliott, for bringing this forward, and I certainly watched that over the course—and my hat goes off to you, and certainly every party. I believe everybody here on this committee is for the best interests of people who have been labelled in this province. I truly believe that, and my simple comment was—taking my hat off, of who I represent as a citizen—this concern is going to still continue to be here unless it's dealt with today. I'm proud to represent an organization that deals with a lot of this, and I can only say that if you get millions of people with disabilities in a room and you go against them, you better have a helmet on, because I can tell you right now that they will speak out, whether you look at different communications. I'll be the one supporting them, so I won't be going up against.

Thank you so much, Jack, and thank you for your comments. I'm proud of the work that I've been able to do over the last eight years, and I know that I look forward to working with this committee, whether I'm with the organization in the coming days or not.

The Chair (Mrs. Laura Albanese): Thank you. Miss Taylor or Ms. DiNovo?

Ms. Cheri DiNovo: Thank you, Mr. Earle. That was a brilliant presentation. I thank you so much for all the work and advocacy you do. I wanted to let you know that, as the poverty critic for the New Democrats, I travelled across Ontario and that the overwhelming answer I got from anti-poverty activists everywhere was not to merge the ODSP and OW, so I wanted you to know that we're committed to not doing that.

You also probably heard me earlier talking about these assessments that go nowhere and result in nothing. It's draconian; it's Orwellian. We should stop doing that.

I have a question about your 9,000 on the waiting list. I've been asking about waiting lists since the beginning of this committee. Boy oh boy, is there a discrepancy. I trust your figures more than the bureaucrats'. I just want to know where you got them. We heard from one of the ministries that there's only 2,300 on the waiting list.

Then we heard there were 4,500 in long-term care, so I'm adding those in, so there's another 4,500—because I'm sure their families and they don't want to be in long-term care. I'm sure they are waiting for something better. So I was just wondering where those figures came from.

Mr. Kory Earle: Yes, and I can certainly put it in an email and stuff like that.

Ms. Cheri DiNovo: Sure.

Mr. Kory Earle: I also want to remind people that we met with the Minister of Community and Social Services in April. His number was a lot higher than 9,000. So I want to remind the committee that he did pull up his numbers as well. I'm using 9,000 people, but it's higher than that. I'm just being safe by saying 9,000.

We got our numbers from work with different partners in this province where they do a lot of figures—just like the 25.9% for jobs. There were a lot of forums that actually developed that. We still don't know how much it's gone down, because there hasn't been an answer to that.

Ms. Cheri DiNovo: Yes. We're doing our own little research in Community Living and through others to try to gain their figures, but I guess it points to the work of MAPS, too. I mean, we just don't have raw data here that's reliable in any way, shape or form, which is absurd.

Mr. Kory Earle: Absolutely.

Ms. Cheri DiNovo: Absolutely absurd.

Anyway, I thank you so much. What you do is fabulous. We'll take everything else to heart that you've got in here. Thank you.

Mr. Kory Earle: Thank you so much.

The Chair (Mrs. Laura Albanese): And now we'll turn it over to Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you, Mr. Earle, for your presentation. I think you did extraordinarily well on your own there.

I want to let you know that I am the parliamentary assistant to the Ministry of Community and Social Services and work with the minister, the Honourable Ted McMeekin. I know he's very committed in the transformation of social assistance in Ontario. A complete review was done by Frances Lankin and Munir A. Sheikh, which provided recommendations, and all of those recommendations are being reviewed now by the ministry and broken into a phased approach. I know you're part of the partnership table as well—

Mr. Kory Earle: Absolutely.

Ms. Mitzie Hunter: So you do have a seat at the table and can make your views directly to the ministry as being a part of that. So there aren't any sudden plans for this merger, and I'm sure you've seen in September 2013 improvements that were made as a result of the work that Frances and Munir have done.

I have a question for you based on a comment that you made. You talked about how people with developmental disabilities can become champions for their own cause. Part of your founding principles is: "Nothing about us without us."

Mr. Kory Earle: Absolutely.

Ms. Mitzie Hunter: That's one of your strong mantras and positions. How do we work with people with developmental disabilities so that they become champions for this cause?

Mr. Kory Earle: Thank you. [*Inaudible*] sat down with Ted. There's no question that he was put in with a whole lot of unravelling to do with this government and other governments.

Let me be very clear, and with all due respect: I did send Ted an email asking him about the merging—no response to date. It's about two months later. So I want to bring that to light, because when I bring an issue forward, I expect a response in the proper manner—because if it's a concern that our members are facing, you can only imagine the stress they're going through.

So to hit on "champion"—talk to them. Walk the life that they're going through. Meet with them. Don't have them meet with you at your office. Meet with them, and say, "What do you want to do? What are the things that you're going through?" and let them tell you, because I can tell you, you'll get an earful, but you'll get an earful in a respectful manner. They will tell you what they want—the same dreams, the same hopes, the same desires as everyone in this room wants.

We don't want to have a system—the Premier said it very clearly on December 9: People with disabilities have been failed by a model of institution in this province. Is that the way that this committee wants to go forward? Is this the way this committee wants to support group homes, in other ways? I don't think so. What I believe in is that if you sit down, and if you chat with an individual, they will give you what you want—but meet them. Start meeting with people who don't have anybody, as well. Talk to them, because I can tell you right now, as soon as they get someone on their side, they'll champion it and they're going to champion it for days, months and years to come.

I want to remind this committee that our board is having an outburst right now. There's a "hiring your own support worker" thing that just came out, that was just launched, and part of that says that ODSP should be used to hire support workers. Part of that was part in that. I can tell you right now, our names are on that. Shame on the ministry for allowing that to happen, because we never once supported that. We opposed it since the very beginning. That documentation I forgot to bring here today; it's on the ministry's website. I want to remind everybody here today: We don't support that, we don't support part of that document, but yet our names are being used on it. As an organization, I take that as an offence and I take that as an insult.

We need to be very clear—I can go back in all the emails—start meeting people face to face. Quit meeting people on the telephone. You'll get better reception. So thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation this morning.

The committee will recess until 1 p.m.

I have to let all the people who are in the audience know that the room will be locked for an hour because

we have a lot of equipment in here, but you're welcome to come back and to continue to listen to the proceedings then.

Thank you very much.

The committee recessed from 1201 to 1302.

MS. ANNE RAHMING

The Chair (Mrs. Laura Albanese): Good afternoon. The committee is back in session. We will start immediately by calling up our first witness for the afternoon, Anne Rahming.

Hello, how are you?

Ms. Anne Rahming: Hi. I'm well, thank you. I've been looking forward to this for a while. Thank you very much for inviting parents to speak to this committee. I'm looking forward to sharing a little bit of my son's story. It's a great opportunity for us. We hope that this leads to some positive outcomes.

Before I introduce my boy wonder, I thought it might be helpful for all of you here to get a little bit of a window into his world and what it's like, so bear with me.

Interruption.

Ms. Anne Rahming: —light when others don't. He gets hypnotized by it, he focuses on it.

Interruption.

Ms. Anne Rahming: No, this is actually supposed to be happening. He needs to have his eyes blocked sometimes so that he remembers what the task is that he's supposed to be doing. Strong smells bother him and are very difficult; his food tends to be pretty basic as a result. He's calmed by cuddles, bounces, hugs and forts with sofa cushions. If this is bothering you right now, then you'll be really happy that I can do this. We'll just move to the next slide, if I can find the mouse. My son can't do that; he's not so lucky.

This is him at the piano enjoying one of his sessions with Erin Parkes, who teaches music to kids with special needs. This is one of the few times in his day that all of those outside sounds don't drive him nuts, and all of that light kind of becomes background noise like it does for the rest of us, because in this environment he is good at something. He loves music; he has perfect pitch. He knows how to do solfège, so he sings the notes and then plays them on the piano and has a great time at it. It's one of the few times that he gets to be a little boy like the little boys that I imagine you've seen over the course of many days as politicians.

Here's another picture of my son with his older brother Neša on the trampoline. As you can see, Mića is a happy child. He laughs easily. He's obsessed with everything that has to do with Caillou and Dora, and our former psychologist in the room could attest to that. We had to do programming around Caillou for a while.

He loves swinging and sledding, and if you didn't look any closer than this photo, you would think he's just what he actually is: a kid, just like Sue McGowan's son; just like Heather Rose's daughter Molly; and just like Autumn Alberelli's twins—who are both at the severe end of the spectrum—Oscar and Sophie.

But all of these kids have autism, and all of their parents are praying that your panel's recommendations will bring long-sought good news from government.

Let me tell you a little bit more about Mića's story first.

Our son Mića was diagnosed at the age of three with autistic disorder and is considered to be at the severe end of the autism spectrum. As you can see from this photo, early years were pretty much what every parent experienced: lots of cleanup, lots of laughter. Not much seemed out of the ordinary until almost year 2.

The quizzical looks started around 18 months and were really quite obvious by the time he was two years old. It was then that we found out he wasn't hearing very much. We flash forward through two surgeries, hearing problems, apnea problems, and finally we got a diagnosis a year later that there was a much bigger elephant in the room.

We were lucky because our retired parents—my husband's in Serbia, and mine in Quebec, both somewhere far away—were able to help us pay for the prescribed intensive behavioural intervention therapy, albeit at a much lower level of intensity than we would have done in a perfect world. Our parents understood that to not act would have been to lose all hope of our son ever enjoying the benefits of adult independence or the simple human joy of connecting with other individuals. I mean, the fact that he loves this great iPad is great—and I do think the iPads are absolutely wonderful for kids on the spectrum—but making friends is even better. To wait until our name reached the top of years-long lists for diagnosis and then for assessment and then finally for intervention would almost certainly have doomed him to a lifetime of dependence on others and, even more sad than that, isolation. As parents, if it was in any way in our power, we had to ensure that that was not what happened to him.

We're not saying anything, my husband and I, that you have not already heard this week, I am sure. Of that, I am absolutely sure. Our son and the other children like our son need intensive therapy now, not later.

I was actually disheartened yesterday when I saw the story, that I'm sure you all saw, of a mother who is waiting for her adult child to get a place in group care so that she can die. The response of the politician who went to see her was, "Well, obviously, the question on the top of everyone's mind is what will happen once you're gone." That is not the top of our list. The top of our list is what we can do to make sure that when we're gone, they don't need us as much as they do now. If we wait until the question becomes the former, we've failed. I'm not saying anything that you haven't already heard.

While it's certainly incumbent upon this panel to address the huge crisis that already exists within the adult community, it's also your responsibility to ensure that the generations of children who are currently being diagnosed with developmental disorders do not experience the same fate. To do this, you need to be brave and you need to move away from the status quo.

As Ontarians, we're aghast when a child with a grave medical issue such as congenital heart failure or leukemia

does not receive intervention in a timely fashion. We're aghast because we believe that we live in a part of the world where we care about our kids so much and we have the fiscal resources to put them ahead of other social and economic issues that make their way onto the political agenda. As Ontarians, the notion that people with other neurological disorders, like cerebral palsy or Alzheimer's, would go untreated for years seems inhumane, and yet we have a system that makes parents wait for diagnosis and then wait for treatment. We are right to be aghast, because we believe that our society has a duty to protect the most vulnerable.

1310

Mića needs your help if he's going to make the most of himself in adulthood. He needs our help, that is for sure, and we're happy to provide it as his parents, but he also needs yours.

In case you're wondering, our son is doing a great job in IBI at the moment. As you can see in this photo, he's also integrating very nicely into an Ottawa Catholic School Board school that he attends every afternoon with the support of an educational assistant. Just over two years ago, he would have reacted to anyone outside of his immediate family more like a wounded animal than a typical human being.

While he continues to have very low verbal skills—for example, he can ask for what he wants, such as, "I want a drink," or, "Give me pizza," which is often what we get—he certainly is not considered to be anywhere close to moderate or high verbal skills.

He adapts well to new routines now. He enjoys reading Dr. Seuss books, to the point of frustration sometimes on the part of his parents. He takes piano lessons three times a week. He looks forward every day, even on PD days like today, to school time and Sunday swims.

These steps forward have not come as a consequence of the benevolent hand of bureaucracy. To the contrary, our family has found out, as so many others have already related to you, that the bureaucracy for accessing developmental services in Ontario, whether it's by design or by evolution, has become a system of closed doors. Any strides towards accessing needed services are viewed within the community as pure luck or as the consequence of parents like us pushing and advocating for their children night and day, and at times knowingly pitting ourselves against other parents to get the few resources that do crop up above the waterline.

We can speak most to the place that the Autism Intervention Program plays within the system, as we've been on that wait-list, gone through those assessments, fought for funding, and we currently design our son's programming under their standardized criteria. As citizens—because we're those as well, not just parents—we were very angry last year when the Ministry of Children and Youth Services silently endorsed the use of clinical continuation criteria by the AIP, going against its own policies and procedures as outlined in Early Learning for Every Child Today. Instead of continuing to endorse the principle that children should be assessed as individuals

with unique patterns of development and learning and not assessed in comparison to others, our children, children with autism at the severe end, are now subject to clear benchmarks that override the common sense of developing programming according to each child's pace in learning and interests.

Teaching to a test and standardizing hours of therapy and programming for children with different challenges is precisely what applied behavioural analysis is not supposed to be about, or indeed the early intervention version that we call IBI. If you look at the program guidelines, they concur with that point of view. However, over the years, the ministry has allowed the AIP regional service providers, what we call the RSPs in our lingo, increasing leeway into how they manage this file, requiring only that they show "success" with wait-list management. The consequence is that clinical arguments are now being used to herd children through early intervention when it is clinically not advisable to do so in the views of supervising clinicians—not in the views of parents, but in the views of the people who deal with them on a day-to-day or month-to-month basis. The new independent review mechanism that we spent so much time setting up is viewed by parents with increasing skepticism, as it's being fed information by the same RSPs and has limited interaction with the parents or indeed the clinical groups that are actually undertaking the care.

In short, neither our government bureaucracy nor we as citizens seem to be in control of how the early intervention system for autism therapy actually works. Speaking from our personal experience, it's impossible to know what effect this has had on our son, but we do know that despite the huge economic burden we now shoulder—because, as you know, the cost for full-time intervention is somewhere in the neighbourhood of \$60,000—the cost has been, and continues to be, for us, worth it.

The system is broken. There is simply too much system and not enough service. We are pleading with you to be brave and to look westward for answers. I know that sounds like a crazy notion. Why would we look west for answers in our country? But I'll tell you what every autism family is constantly debating in this province: If you have a kid at the severe end of the spectrum, how do you get to Alberta?

The province of Alberta begins from a very different place than we do. They begin with the family, and they ask, "What can we do to ensure that the family will thrive with a child with special needs?" We're asking you to think along the same lines. Stop spending the money on a bureaucracy designed to tell us that we don't have the money to do the right thing, and instead spend the money or redirect the money to families who provide the documentation that their children need help today.

A direct funding system is more efficient, more flexible and more effective for our community. We can see the success rates in Alberta—and I feel sorry for Alberta because they're experiencing an influx of us, but there you go. The point is that that is supposed to be the point. It should be a flexible, efficient and effective system that

uses taxpayers' money in the most fiscally responsible way.

We—and I'm talking not just on behalf of my husband and myself, but we in the autism community here in Ottawa and beyond, because I now participate in a number of communities of parents across the province—have heard three statements over and over again as we advocate for direct funding as the new system for autism service provision. Usually they come from people who are within the bureaucracy or from people who have studied the bureaucracy in the past. "What about the places in Ontario where there is no direct funding? What about the poorest people in Ontario on the waiting lists? Wouldn't parents just abuse the system if they got the money directly?" Those are the three questions that seem to crop up over and over again.

On the first point, it is true that some regions of Ontario, particularly the northern region, may be challenged by the lack of private providers at the moment. But keeping a monopolistic system in place does not create new providers. We are not advocating for doing away with the organizations. Every region has an RSP at the moment. Putting the tax dollars back in parents' hands and having us either purchase services from the RSPs or from private ones creates real competition in every region and across the province.

I should add—which I didn't have in my notes—that, for example, our current senior therapist is on a flight internationally to go and do a face-to-face supervision with a child that she has not actually seen face-to-face for over a year but has been supervising via Skype. So the idea that a single region not having private provider availability should be driving the current system becomes a moot point in an era where Ontario is increasingly connected through the Internet.

The status quo is actually quashing competition, and, more to the point from the standpoint of our tax dollars, it's raising labour prices in the market. I'm not advocating that we should start paying our therapists minimum wage, because they do a really, really difficult job. But when we have a wage gap that is, in some parts of the province, three times as much being paid to an RSP's therapist versus the private provider's therapist, all that you get, for those of you who have done labour economics, is a push upwards; it's never a push downwards on the prices. And it's the parents who pay the cost of that and, ultimately, the taxpayers as well. The status quo is also raising labour prices in the market, which will make it only that much more expensive for us to continue to fund the same system over time.

On the second point that I made earlier, my husband and I have a lot of trouble not getting angry. I should add—and my MPP, Jack MacLaren, is in the room, and knows my husband—that my husband is a new Canadian from Serbia who came to this country and worked 18-hour days at minimum wage jobs for the first two years that he was here without stopping—six days a week. When you talk about the poorest people and how you're going to help them, he usually perks up to find out if he would fit himself into that mould. The poorest parents on

this wait-list are the worst-served by the current system. To say anything else and to put the current system as a reason for being on their back is a lie and is egregious.

1320

They are the most likely to have minimal parent training, as they struggle to make ends meet, and more so than other parents who are also overwhelmed are challenged to make it to the intermittent parent-training sessions that are offered. They are also most likely to wait for service and pay for no therapy during those critical early years of their child's development. As a consequence of both of those factors, they are most likely to be the parents of children who develop extreme behaviours that will stay with them into their teen and adult life. In what way is that a system working for them?

Finally, the notion that parents of children with autism, particularly those with severe autism that never sleep and bounce at 4 a.m. in the morning, will go wild and spend funding on a drinking binge or at a casino is absurd. We are struggling every day with children who have a severe disability. The last date night we had as a married couple was two years ago. Do we sound like the kinds of parents who are likely to abuse the system? What concerns us, in fact, is that so much energy seems to be put into worrying about us abusing the system and so little into the fiscal abuse going on within it by those holding the fiscal purse. How did that happen? From where we stand, the onus is on us, our son's parents, to ensure that he succeeds. To do that, we need to be able to use the fiscal resources that are available as wisely as possible so that we can provide, as the program guidelines stipulate, high-quality, evidence-based intensive behavioural intervention—nothing more and nothing less.

Redirect funding to the families and you will find, first of all, that we have a more efficient mechanism for using the services available in our province and, secondly, that we will have a better long-run clinical outcome for the growing community of children being diagnosed with autism spectrum disorder today. Thank you for listening.

The Chair (Mrs. Laura Albanese): Thank you for your presentation, an impeccable presentation, I should say, very well-presented. Unfortunately, we don't have any time left for questions or comments. Jack, don't look at me like that—I have to be fair and allow the same time for everybody. But we really appreciate your comments and your recommendations to the committee. We will keep them close at heart. Thank you.

Ms. Anne Rahming: Thank you very much.

ONTARIO RESIDENTIAL CARE ASSOCIATION

The Chair (Mrs. Laura Albanese): We'll call now on Ontario Residential Care Association to come forward. Good afternoon. Make yourself comfortable.

Mr. Len Goddard: Good afternoon, Madam Chair and all MPPs from all political stripes, I understand—and I hear you're working as a harmonious group.

The Chair (Mrs. Laura Albanese): Yes, we are.

Mr. Len Goddard: That's a great experience, eh? Congratulations.

The Chair (Mrs. Laura Albanese): Thank you.

Mr. Len Goddard: My name is Len Goddard. I'm the president of Ontario Residential Care Association and also the executive director of Sonshine Families.

Who are we? I deliberately asked one of you earlier if they knew what an OPR was—nope. We'll tell you. Part of 100-plus OPRs across the province, we provide residential respite and other support services to children, youth and adults. OPR means outside placement resource. We are part of the system, but we're outside the TPA block. Our members are one or more of the following: for-profit, not-for-profit and registered charities. However, we all operate on a fee-for-service basis, which means we are only paid when we are actively serving a client. There is no guaranteed ongoing funding and no capital investment by the government. Our services fall under the ministries' regulations, including the QAM—quality assurance measures, and we're reviewed on that regularly.

Interjection.

Mr. Len Goddard: Did you want me to stop for something? Oh, okay.

We provide many of the services to our citizens with special needs such as the following:

- group homes, with a wide diversity of client profiles, some for males, females, children through to senior citizens;

- foster homes with parents and staff educated and trained in the care of special-needs clients;

- respite programs using facilities in the city, in camps and homes, and again with a diversity of programming that meets the clients' needs; and

- day programs that include services to total-care, dually diagnosed clients, as well as work programs. Recreational, educational, vocational and rehabilitative needs are provided for.

Some of our member agencies have been involved in providing services and have been active in this field for several decades. We have successfully demonstrated the ability to quickly adapt our programs to meet the specific needs of individuals. We often receive very challenging clients that are not able to be placed in many TPAs. We believe in and are committed to providing our clients with the best possible quality of life. We are often frustrated by the pain that the system can inflict on many of our clients and their families.

I'd like to ask Margo Babe, who's the adult service manager of Sonshine Families, to share but a few of the stories drawn from our agencies across the province. I will share our recommendations when she is finished.

Ms. Margo Babe: Good afternoon.

So how does the current lack of a comprehensive collaboration of ministries affect families in our community? What happens when funding is not individualized or portable?

Unique individuals require unique funding solutions. This requires ministries to work together to provide sup-

port for different areas of life. A person-centred plan designed around a person's individual needs must involve family, friends, school and community members, but must also have a government and ministries willing and able to create a circle of support, which includes a circle of flexible funding. Because of the current inability to provide such a circle, the system is failing many of our citizens who require support.

Here are some examples.

A gentleman with a developmental disability and some aggressive behaviour has successfully been supported at a group home for several years. He fell and broke his hip. The group home could continue to provide services but requested funding for renovations to make his home accessible and for some at-home medical supports. However, this was not available, so the gentleman remained in hospital for a long period of time.

Children who are in care of CASs with multiple complex care needs such as autism, Asperger's or fetal alcohol syndrome, for example, intellectual disabilities and mental health diagnoses, or intellectual disabilities and physical disabilities, i.e., complex care needs: They have found a successful placement in foster or children's group care, but because they have a birthday—i.e., they turn 18 or 21—they are now under adult services, and even though the home they have lived in for many years is willing and able to continue providing the support they need to be successful, they must move because adult services does not have the ability or desire. Agencies have been told, "We do not work with for-profits." This is also a problem for providers of respite for children who have worked with families for years and are able to provide excellent care because of the relationship and knowledge developed over these years. This child now becomes an adult by age and cannot be provided respite in this home because of no available funding.

We need to support the development of lifelong care plans and providers with lifelong relationships and knowledge.

Another example: a young teenager with a developmental disability who requires support for all areas of activities of daily living. She's blind, she is non-verbal, she requires a wheelchair for support, and she can at times display self-injurious behaviours towards herself and others. She lives at home with her single mom and younger brother. An agency begins providing support by taking this young lady to camp in the summer, and then the same agency is able to provide support at their respite program in a group home. Mom becomes pregnant with twins. Her teenage daughter now requires immediate placement for at least six months to a year, as the family doctor says mom cannot continue the primary care because of her pregnancy-related health issues. The agency that has been providing support for over five years offers to care for this lady. However, because this is considered new funding needed, the family is only offered placement in group homes, which are transfer payment agencies, which have vacant beds which are funded. This young lady is placed unsuccessfully in two such homes, and the

family and client are traumatized and still left without support. The original OPR agency now cares for this person five days a week out of compassion and highly subsidizes the cost from funds they really don't have.

Another example: At a recent meeting, children and adults with fetal alcohol syndrome were identified as falling through the cracks because they require support across different ministries, such as the Ministry of Community and Social Services, the Ministry of Education, the Ministry of Health and the Ministry of Correctional Services. Because this cannot be organized, many of these individuals end up in jail.

For example, a young man with fetal alcohol syndrome and a developmental disability was living successfully with loving support in a foster home. When he became an adult—he had a birthday—because of the funding, he could no longer stay there. He ended up returning home to his biological family, who were not able to care for him. He then ended up in the wrong crowd, and with a "friend" robbed a McDonald's. However, the next day he felt guilty, so he returned to the McDonald's—if he hadn't returned, he likely would not have been caught—and confessed. He was arrested and ended up in jail. One of his issues was picking at his cuts. He cut himself on a food slot in his cell and picked at it until it became infected. He ended up dying from blood poisoning. The system failed and, I would say, abandoned this young man.

Another example: A gentleman with a developmental disability and mental health issues has been involved with the justice system and has been threatened that any more such involvement will result in a jail sentence. This individual is in no way equipped to survive jail time.

1330

Temporary short-term funding through Service Coordination Ottawa has been found, and he is successfully placed in an OPR group home for adult males. But what happens when this funding runs out? We need not only the Ministry of Community and Social Services but the ministry of justice and mental health to come together to provide the support needed to allow for continued success and keep this young man out of an expensive jail cell.

Another example is a vivacious, outgoing, full-of-life young woman in her early 30s who has cerebral palsy, which affects her ability to walk, speak, eat etc. She requires help with personal care. She has lived her whole life with her parents, with her mother being the primary caregiver. Her parents are now elderly, in their seventies and eighties, and, for the first time, start to look for immediate respite care.

They find a service they are happy with, which provides respite service in the form of summer and winter camps. This young woman attends these camps for several years and forms strong bonds and relationships of trust with the caregivers. Then her mother passes away. Her father, with help from some aunts, continues to care for her, but the father and aunts are in their eighties now.

The father now requires a residential placement and would like to place his daughter with the same agency

that provides the respite at camp. This agency can provide an appropriate residential space with the same consistent caregivers and an active day program, which would meet her social, mental and recreational needs for a vibrant woman of her age. However, there is no way to access funds.

Instead, this young lady is placed in a nursing home where the rest of the patients are elderly and frail. This bed is not less costly, just one that is block-funded; however, this is not an appropriate placement for this young, vibrant woman.

Our last story will be presented by Tina Kokkinos. She's going to speak about her sister.

Ms. Tina Kokkinos-Marins: Hello, my name is Tina Kokkinos-Marins. My sister is Nikki Kokkinos, who is a 43-year-old autistic adult with no verbal skills and behavioural issues. She was the unlucky one who didn't get early treatment. Now she is 43, and there are huge issues.

Nikki has always lived at home, and in 2005, our mother, and Nikki's main caregiver, passed away, leaving my father to care for Nikki on his own. She attends a four-hour day program at OCL since the age of 18. It has now become overcrowded, and Nikki gets no benefit from it and just sits there. But they tell us that the spot is funded and untransferable, so we can't look for a better-funded day program for her.

We have been hiring caregivers in our home to take care of Nikki, but it is very disruptive since there is such a high ratio of turnover with caregivers who come in the home. My father and Nikki are alone in their home, and I am always worried that I'm going to get that dreaded phone call when something has happened.

Nikki was assessed by DSO two years ago and was placed on the priority list, and due to the urgency of her care, a service coordinator was assigned.

Finding a placement for Nikki seems very difficult. She is extremely vulnerable and has behavioural issues. As well, the family's main priority is for a secure group home.

Our case manager was able to find Sonshine Families as a respite for us. She loves it there, and we love it there for her. But we've been told that this is a private agency, and it can't be funded. They won't fund it for us.

We've gone through service resolutions, contacted the Ombudsman of Ontario, as well as our MPP. We've received absolutely nothing.

We pay out of pocket for respite for Nikki right now at Sonshine Families. She is happy; we are happy.

It is only a matter of time before something happens. My father is 82; Nikki is 43. It's only a matter of time before my father, who has had two heart attacks, will have one and will pass. Nikki will be alone in that home.

They tell me that she will be taken and placed in a hospital. It seems ludicrous to us that the ministry would pay for a hospital bed that costs five to six times more than a spot at Sonshine Families group home. It just seems ludicrous. The fact is, she won't be able to stay there. She has huge behavioural issues; the hospital won't accept her either.

It's like I said: It's only a matter of time before something happens. The question here is, when it does, who is liable? Will the government not be liable for neglect? We often ask that question. I have my own family, I work—we've exhausted ourselves, and I know many other families in the same boat. But when a family finds a placement where you know your loved one is happy, is cared for and you can at least have some peace, and they tell me we can't have funding because it's not a funded spot—we don't know where to turn. It's just impossible, and it's unbelievable. With direct funding, we would use it for the place that is perfect for Nikki.

One more thing: Without direct payment to families to find good placement—it allows for competition. There are, right now, I know, funded positions. Even in the day program she goes to, it's funded, but it's not any good anymore. It's overcrowded. With money direct to us, there would be competition and people would find better places.

Mr. Len Goddard: How can these challenges be better met with existing funds? Services must be more individual, client-centred and focused. The development of the DSO system is positive, particularly the evaluation and assessment of each unique individual's needs and the level of care these needs require.

I sat on the ministry's systems planning table when transformation of the adult system was under discussion. At that time, there were to be two parts to transformation. One, the assessment and evaluation piece, has been implemented. However, the second part of the transformation of funding to an individualized funding model that is implemented based on the assessment that has been done has not happened. Somehow, the old system of block funding was retained. That wasn't the original plan. Money through the DSO could be client-focused, not agency-focused. Funding must become attached to the client, not to agencies. This will enable the system to provide for more unique, efficient funding to be used in person-centred planning. This individualized funding would allow services to be developed around a specific client, with the input and the involvement of the family and the entire support circle.

This type of funding would also be able to follow the individual through the different stages of life. This would mean that perhaps a child could even have funding that could move with them into adulthood. This would involve a shift in thinking from block-funding large institutions—schools, agencies, hospitals, and even corrections programs and prisons—to funding individuals based on their assessed needs. Hopefully, this would allow support to happen in the community and reduce the need for the services of these large, costly entities.

The DSO could manage these funds. Hopefully, this would also prevent the passing-of-the-buck syndrome between ministries that takes place now. We could create a model in which all ministries of the same government could work together to provide better outcomes for all individuals and their families with special needs in Ontario.

Don't opt for a hospital or correctional bed at \$1,500 to \$2,000 a day when a bed or services that are six times

less expensive could effectively provide the care required, while maintaining continuity for the client. For accountability, one ministry could take the lead.

We owe it to our communities to make the system accessible through shared services between all ministries, at the same time ensuring that service is provided for every dollar spent. Respectfully submitted.

The Chair (Mrs. Laura Albanese): Thank you. We can allow for about a minute's comment from each party. Continuing from this morning, it's the NDP's turn.

Miss Monique Taylor: Thank you so much. Thank you all for your presentation. Bringing perspectives to the table of different clients who don't have a voice or somebody to advocate for them is so important, so thank you for that a piece of it. Thank you for sharing your sister with us and the troubles that you're facing, because it is a crisis, what's happening in this province. You're not the only family that's going through this, and I don't say that to belittle what your family is going through. I say that because we understand, and it's so wrong, and something really needs to happen.

1340

We have to be looking at other scenarios of how the funding is being directed. Direct funding is something that we've heard a lot of families saying is necessary. Some families aren't able to deal with that direct funding, and we understand that. We can't have a cookie-cutter situation for everybody in this province. Families are individuals and need to be treated as such.

Thank you all so much for being here today.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you so much for taking the time to be with us today and for articulating each of those stories. It really helps to focus us as we're looking now to get into the stages of drafting our report, having conducted our hearings across the province. We are hearing some common themes. So I want to say thank you for that.

I note that you have some specific issues that are relating, and you're trying to get the attention of the ministry, of your local member. I think that that's very possible, so that you can get the assistance you need to get the answers that are available. We'll ensure that we follow up with you on that as well.

The Chair (Mrs. Laura Albanese): Ms. Jones?

Ms. Sylvia Jones: Thank you for your presentation. I think what you've done with your examples and your family experiences is shown the need and the value for different services along our life, just like all of us.

While I would never question you, Len, I do have one question.

Mr. Len Goddard: Sure.

Ms. Sylvia Jones: In your first point, you say, "The development of the DSO system is positive, particularly the evaluation and assessment...." I have to tell you, we haven't heard a lot of that. We've heard a lot about, "Why is the DSO assessing my child for a diagnosis that we were given 15 years ago, 16 years ago, 18 years ago?" Without putting you too much on the spot, why do we need another assessment at that 18-to-21 age?

Mr. Len Goddard: I think that what the system has learned previously is it was often the squeaky wheel that got the grease, and the decision was made that we need to evaluate everyone on an equal footing so that apples are compared to apples, not to oranges. So that's what the DSO is now doing.

I don't think there's as much complaint about the DSO in the assessments—at least, from what I'm hearing—as that when you make the assessment, nothing happens afterwards. It's a dead end.

Ms. Sylvia Jones: Yes, we are hearing a bit of, "If I already have a medical diagnosis, a medical assessment, why are you forcing me to go out and get a psychological assessment?" That's an added cost to the family, and I'm just wondering what the value of that is, other than a bit of a make-work project.

Mr. Len Goddard: Yes, I hope it's not that. I would just say that if we have two or three assessments from two or three different people—for different clients, from different professionals—you have to have some means by which you can evaluate it fairly and equally. I think that's what the system's trying to do, so that when you grade it later, as to who is in grade 1, 2, 3 or 4, as far as needs, you know you've done a fair, equal assessment.

The Chair (Mrs. Laura Albanese): Thank you. That explains it for us in clearer terms than we've heard until now. Thank you very much for your presentation this afternoon.

Mr. Len Goddard: Thank you.

OTTAWA-CARLETON ASSOCIATION FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

The Chair (Mrs. Laura Albanese): Our next presenters are the Ottawa-Carleton Association for Persons with Developmental Disabilities. Welcome. As you may have heard previously, you have up to 20 minutes for your presentation. Should it be shorter, that will allow for questions and comments.

Mr. David Ferguson: Good afternoon, and thank you to all of the committee members for your participation in this process. It is appreciated by this sector.

My name is Dave Ferguson, and I'm the executive director of Ottawa-Carleton Association for Persons with Developmental Disabilities and Open Hands. With me are Bill Cowie, president of the board of directors of OCAPDD, and Bonnie Dinning, past president of OCAPDD and current board member of OASIS.

Having followed the transcripts of the committee, we were certainly aware that it has been a challenge around time and opportunities for questions, so we are going to attempt to limit our comments, or shorten them, to invite time for more discussion.

Bill's going to talk about OCAPDD's work with regard to establishing a national coalition, and Bonnie will speak to her experience as a parent of a young man with a developmental disability and the innovative residential service that has been created for him. I will share

a few comments about OCAPDD and also the issues facing the sector in Ottawa.

OCAPDD is similar to many community-based developmental service sector agencies that you're familiar with and will have heard and received presentations from, from across the province. We've been operating for almost 60 years and provide a full continuum of community-based services. We provide approximately 1,000 individualized services per day, operate with a \$25-million annual budget and employ 550 staff.

In 2007, OCAPDD began managing Open Hands, a DS sector agency in Cornwall, and two years later amalgamated it with OCAPDD. Also, for the past three years, we have been providing financial and payroll services to another Ottawa-based DS sector agency on a contractual basis. Also of note, OCAPDD was one of the first six organizations that formed OASIS in 1996, and we've been very actively involved with that organization since that time. In fact, I've spoken with some of you before in my role as chair of the OASIS labour relations committee.

OCAPDD and other DS sector agencies in Ottawa and eastern Ontario face the same challenges as others across the province: long wait-lists, frozen resource levels, increased operating costs and pressures including wages, pay equity and reduced capacity and ability to respond to service requests. Two things that are different here in Ottawa are that Ottawa has had a central intake process for approximately 20 years, and also what I would call managed competition, and I think the presentation just before us spoke to that as well. The central intake process here had been with Service Coordination for that period of time. We've gone through the process and have had the experience here—that other parts of the province are just going to—of having that distance, if I can describe it that way, from families on the wait-list, which has been frustrating for those families and frustrating for organizations.

With the managed competition, it has existed through the OPRs, and Len has talked about that. From my perspective, there is nothing wrong with that managed competition. I believe it's starting to spread across the province, and I would agree with many of Len's comments. The issue from my perspective, however, is it's not so much the direct funding issue; it's more about an entitlement or rights-based service. We can speak more to that later.

One other unique aspect to the DS sector in Ottawa is that there was a period of time here when several agencies had been declared hospitals by the labour board and the Minister of Labour. When a hospital, we were covered by the Hospital Labour Disputes Arbitration Act, or HLDAA, resulting in a no-strike, no-lockout environment. This was changed by legislation in 2001, and, as you are no doubt aware and referenced earlier in the session today, the sector is now subject to strikes. And again, you aware that this spring, there is going to be a serious threat of work stoppages in this sector in the province—obviously, a concern to many of us.

Before I ask Bill to share his comments, I would like to make one follow-up comment to Dr. McCreary's presentation this morning. We had an individual we were supporting who was having severe challenges, and he ended up in the hospital, in the emergency department. He had severe behavioural challenges, and the staff were working with the psychiatrists there, and the psychiatrist's comment was shared with me later. He expressed it out of frustration, not out of any kind of condemning or demeaning manner, but his comment to my staff was, "I feel like I'm a veterinarian. My skill set is completely gone"—because his skill set was based on verbal discussions and communication with his patients. So I certainly support the recommendations in terms of the training for the medical community. It is urgently needed. I was quite surprised and pleased to hear about the amount of attention that the UK provides in that.

With that, I will turn it over to Bill.

Mr. Bill Cowie: Thank you, Dave, and thank you for this opportunity to address the select committee. We welcome this chance to present to you some background not only in the issues we have faced as Ottawa's largest service agency for the developmentally disabled, but also on one of the initiatives we are taking now to address them.

Dave Ferguson and I have spoken, and he has identified for me at least three broad areas of stresses in the system that need to be addressed: the issue of competitive wages for people who are providing services in this sector, the whole issue of capacity-building and organizational development, and, of course, the waiting lists.

1350

In the past year, one of the ways we have tried to address these sectoral issues is to try to broaden the discussion in order to bring more players to the table, specifically by promoting a national strategy or program for the disabled. The need for and feasibility of such a strategy has four primary sources and clear indications that the provincial resources were limited and that all of the problems would not be able to be addressed at that level, at least not in the foreseeable future.

Second was the Drummond report recommendation 8-9, which recommended engagement by the federal government in supporting individuals with disabilities, especially those who are unemployable.

The third driver of this initiative was the Australian example—the introduction of something called the National Disability Insurance Scheme in Australia—and the existence of similar programs in Germany, the UK, New Zealand and elsewhere.

Finally—and I think you will attest to this. I've been on the board a number of times. This is my second round as president. When I came back a second time, I saw the same discussion with the same people saying the same things when I was on the board before. The system was in stasis. We talked about all the marginal changes and so on and so forth, but the critical elements of the system were not changing and the debate was remaining the same. The discussion and the discourse needed to

change, or at least start to be more hopeful is more the word that I want to use here.

Our purpose is to tap federal resources with the province's so as to enable the building of a universal insurance or support scheme for the disabled that is, as I say, universal and comprehensive. We believe that only with this approach can the challenges of the sector, which I have identified and which are decades old—only then can they be addressed. Those are the issues of waiting lists, strengthening organizational development, capacity-building and competitive wages.

With this in mind, our first primary task was to bring the communities involved with the disabled together in the cause. I will put my appeal out there right now to everybody in this room to join us in this.

To that end, we are working in five streams. First of all, we are fostering partnerships and cultivating allies for promotion of this agenda wherever we can find them. I've been in touch with some of the organizations in this room. We've also been in touch with Ryerson University and the disabled studies group, and we are also getting support from OASIS for this, leading towards what I hope will be the creation of a national coalition.

The other thing we're doing is drawing attention to our efforts from members of Parliament, in the Senate, on the Hill, and mobilizing the political community to the cause. We have met with senators and members of Parliament, with further meetings planned when Parliament returns. It is our intent to engage all parties in the debate, and to date the response has been very encouraging and supportive.

The third thing we've done is we've undertaken research to better understand the national picture, both in its similarity and diversity. In this, we've received some federal funds for research, and we have a summary report on our findings. What is interesting about that is the commonality of problems across provinces.

In addition, one of our board members, while in Australia, conducted research on the Australian model, asking the particular question, "How did you manage to do it? How did you create a universal social program in this time and age?"

Most urgently, we're working to find the resources to create a national secretariat to carry out the administrative load that this is going to require as we move forward, which is something beyond the capacity of our particular board to do.

We are also soliciting support locally and provincially—as I say, engaging OASIS and Community Living. Even as recently as yesterday, we were presenting both to OASIS and Community Living in that cause.

What has been encouraging so far has been the response from Parliament Hill. Numerous Senate reports and others over the years have addressed this issue, and the push from below is being very welcomed. In fact, the discussion has been going on on the Hill quite extensively, but what they have lacked is the national push from below.

What is problematic for this agenda is that the community of the disabled is so fragmented. Many different

players coming to the table and a more unified voice would be most welcome; that is why the need for a national coalition.

The other problem, and I saw this in some of the presentations this morning, is data. We saw this when we were trying to do the provincial studies. We know so little about each other, about our standards, what works and what does not work, and what is the magnitude of the problem. Without better data, any national program would be making policy in the dark, and that clearly has to change.

The initiatives do not address the immediate problems of this sector. We are talking the long game here, but it is a game worthy of engaging and represents only one more link in the chain of improved support for people with disabilities that began in earnest almost 60 years ago.

Thank you.

Ms. Bonnie Dinning: I have a good-news story to tell you. In 2007, MCSS released a call for proposals for innovative housing models. In response, two families, of which one was mine, approached OCAPDD with the idea of forming a family-agency partnership to provide housing for our sons. The proposed model involved the purchase of a home by the parents, the provision of personal support by the agency for the sons, and conflict-resolution support to both parents and sons.

Conflict resolution became an important support that the agency provided. It was something the families could not have undertaken on their own. It eventually became clear that the sons were not well matched for living with each other, and one family left the partnership. The agency took on the role of creating a new match, which has been very successful.

So why am I telling you this story? I believe this is an example of an incentive that has allowed two families to invest in Developmental Services Ontario. I've been active with family community groups over a long period of time and, more recently, was the founder of United Families of Eastern Ontario. I heard, many times, families saying that if only they had some support, they could create solutions for themselves. This project allowed us, as a family, to do that. It also allowed us to remove two people from the waiting lists locally, both our son and also his current housemate, who has no family to assist her.

I also believe it's an example of how families can access quality support. Unfortunately, purchasing services from an agency is usually beyond the financial ability of most families. I really do hope that as you develop your report, you will consider ways to make the valuable resources which are currently available for those supported by agencies available to those who would like to purchase them. We need access to supports that are more viable and financially available.

That's all I have to say today. Unless any of my colleagues have any other further questions, we would like to give you the opportunity to ask us questions.

The Chair (Mrs. Laura Albanese): Yes, and we do have about two minutes for each party, starting with the government side. Ms. Wong, or Mr. Fraser?

Mr. John Fraser: Thank you very much for your presentations. Thank you very much, Dave, for the work that you do and, Bill and Bonnie, for the volunteer work that you do.

I want to ask a question in regard to the example that you found in Australia and what you're proposing as a national strategy, if you could flesh that out a little bit more in terms of how that looks from a policy perspective—if you've got that far.

Mr. Bill Cowie: Australia, as you know, has a governance structure much like Canada. It's a Westminster model under a federal system. The states were responsible for the developmentally disabled and, like in Canada, there were unequal services across states and unequal services within states: different standards and different priorities.

Through a really magnificent push—a bipartisan effort, in the case of the Australians, with strong political leadership coming from key people in both parties—and as a result of a committee that was struck under the prosperity commission, the ministry of finance led the charge on this, in a document called Pay Now or Pay Later, in which they basically made the argument that if you don't put your money into the needs of the developmentally disabled early and extensively and comprehensively, you will pay a lot more later. That's what opened up the discussion, and that's why it became largely an economic discussion rather than a rights discussion.

In the end, when they went through all of this, and through very strong financial supports for promotion and an excellent advertising campaign—we've documented all of this and we have presentation on this—it ended up, by the end of this cycle, that the Australian people as a whole just ended up saying that, economics or not, it was the right thing to do.

Mr. John Fraser: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. From Mr. Fraser, we'll go to Ms. Elliott.

1400

Mrs. Christine Elliott: Thank you very much for your presentation. I think it's really an intriguing idea and something that we would like to know more about.

I just made a note here that you mentioned that you got some federal funds for a study, that you had a—

Mr. David Ferguson: We applied for a summer student grant and received a small amount of money and were able to hire a university student who did the research for us over a number of months.

Mr. Bill Cowie: A genius, by the way.

Mrs. Christine Elliott: Is there a report available that we could—

Mr. Bill Cowie: Absolutely.

Mr. David Ferguson: We certainly have the presentation that was made to OASIS over the last two board meetings. We can certainly submit it to the committee.

Mrs. Christine Elliott: Terrific. That would be very helpful. Thank you.

The other thing—I just made a note, Mrs. Dinning, of the comments that you made: if only families had some

support they could create solutions for themselves. We believe in that too. One of the things that we're looking for, as part of this committee, is innovative housing solutions, because we know that we cannot eliminate the current wait-list by doing the same things that we're already doing, and that one size doesn't fit all. Individuals need different supports depending on their needs. I just hope you know that we will be bearing that in mind as we go forward.

Ms. Bonnie Dinning: Great. And I'm aware that the committee was working on that, so that's great to hear it's going to move forward.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you very much for your presentation. A couple of questions—absolutely, it's coming through loud and clear that we should have a rights-based system, an entitlement-based system and not a discretionary, i.e., welfare-based system. That's come through very, very clearly, and I don't think we argue with that at all.

We are a provincial body. We would love to see the feds step up, but in the meantime, we've heard good things about what's already happening in Alberta and Saskatchewan, primarily mandating an end to wait-lists, for example. In a sense, it's a step towards what you're talking about, but if you mandated that, the funds would have to follow. So starting at the mandated, I was wondering if you could comment about that.

Mr. David Ferguson: Again, I think that's fundamentally the issue, from our perspective. Like education, like health, if every Ontario citizen who had a developmental disability was entitled to some resources—we're not here saying it's the same for everyone—an individualized approach. But the fact that there would be resources there for them through their life, that, we believe, would address those three chronic problems that this sector has faced for many, many years.

I think that one of the aspects of why this is coming to a bit of a crisis, ironically or indirectly, is as a result of the closure of the facilities. Although that's been really positive, that was a buffer in the system and that was an entitlement system. Lots of people didn't want to be there and shouldn't have been there, but that's where a lot of the challenging individuals ended up. Those people are now being supported in the community and putting pressures on all aspects of the system.

Ms. Cheri DiNovo: Right. Okay, thank you very much.

Mr. Bill Cowie: If I could just add to that, one of the things we discovered in our cross-Canada survey was there were a lot of myths out there about whose program was good and whose wasn't. We've discovered things—we would be surprised by some of the results. The Saskatchewan one, where they went after the waiting list, was an interesting example. We need more detail on that. Alberta is having some issues of communication and coordination and of engagement of parents. It's caused a bit of an issue out there.

Ms. Cheri DiNovo: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Very interesting to know. Thank you very much for contributing to our discussion here and presenting to the committee.

FAMILY ALLIANCE ONTARIO

The Chair (Mrs. Laura Albanese): We will now call on the Family Alliance Ontario to come forward.

Ms. Cindy Mitchell: Karen Inwood is one of our board members. She's going to hand out the documents to everyone.

The Chair (Mrs. Laura Albanese): Thank you, Karen, for handing out the documents to us. It's Cindy Mitchell, right?

Ms. Cindy Mitchell: Yes, my name is Cindy Mitchell.

The Chair (Mrs. Laura Albanese): You may begin any time you feel ready.

Ms. Cindy Mitchell: Okay. Thank you. My name is Cindy Mitchell. I'm vice-chair of Family Alliance Ontario. Our president recently resigned and moved back to the UK. We've heard a lot about the UK system. She actually moved there for better services for her daughter, and she now has better services. She had that in less than a few weeks upon arriving.

Who is Family Alliance Ontario? FAO is an alliance of citizens that offers knowledge, tools and networking opportunities to individuals with disabilities and their families, to assist them to realize a vision of having really good relationships and choice and control in their lives and by enabling inclusion and meaningful contribution and participation in their communities.

Family Alliance Ontario is volunteer and not-for-profit. We're a provincial organization composed of individuals who live with disability, of families and of their allies. Our allies include 14 family networks across Ontario. I'm happy to say we have a couple of members of Family Alliance from Ottawa here in the audience.

Throughout this brief we will say "families." When we use that term, we include parents, grandparents, siblings and others who provide direct, non-paid care for someone they love, as well as friends and advocates for individuals who do not have a family to help or support them.

FAO has represented the individual and family voice for over 20 years. We have provided position papers and we've attended focus groups with the ministry, with community and social services, and with members of Parliament to express our concerns about the system.

With this presentation, we—and I, because he's my friend and he was my boss—are remembering Peter Dill, an activist, a parent, a trailblazer, a long and tireless advocate for full and authentic inclusion for people with developmental disabilities as equal and full participants in society. This past week, Peter's family, Ontario families, family networks and people with disabilities and their extended families and supportive networks lost a steadfast leader. He was an ED of an association. So

leaders in associations exist; parent leaders exist out there. We need to get back to that.

I'm really pleased to be able to present to you on behalf of the FAO. As you've already heard over the many days of hearings, the current system really is devastatingly broken. You've heard from the assistant deputy minister of social policy development for community and social services that MCSS is on a journey. This journey has taken 10 years and it's taking too long. We say "bad," because in its development logical, sound and transformational amendments that were presented early on were ignored. We continue to be disheartened by the length of this journey.

In 2004, when the journey began, the then Premier, Dalton McGuinty, described how broken the system was, and I'm going to quote him. He said that "there are parents out there into whose arms is born a child with special challenges, and I just have the greatest admiration for them. It's 24/7, 365 days a year. They can never let up. And they fight and they kick and they scratch and they claw when it comes to securing government services, because they want what you want and I want for our kids"—what everyone wants. "They just want the best."

Mr. McGuinty did get it right when he identified the struggles, but he also got it wrong. People are not expecting the government to provide just the best; they're expecting their children to have just an ordinary, typical life, the same as anyone else in Ontario. Some just need a little bit more support. Is that not what it means when we hear that it takes a village to raise a child? What is even more disheartening is that the struggles have become worse and people are now scratching, clawing and kicking to secure services but end up at the bottom of a wait-list.

This is why we are pleased this committee is tasked to develop recommendations and a comprehensive strategy that encompasses all of you working together. That's absolutely wonderful. We're very encouraged by this.

FAO believes that every citizen is entitled to a regular, ordinary life. Every individual, regardless of challenges they face, has a talent and has gifts to share and contribute to those around them. Every person can participate in their community. They just may need a little bit of support to do so. The level of support required varies with each and every person. This is why one size doesn't fit all, and you've heard this over and over again today.

In her apology to survivors, Premier Wynne said, "[W]e strive to support people with developmental disabilities so they can live as independently as possible and be more fully included in all aspects of their community."

FAO and all the people you've been hearing don't see this happening. We hear from more and more people and their families of the inability to get necessary supports to participate. We have some of these stories included at the end of our submission, but it's way too long for me to get to it. You'll notice I'm not reading directly from what you have; I'm kind of covering some of it off.

We've included those stories and we have noted that individuals have been cut off from supports that they depend on to allow them to participate in community simply because they've had a birthday—they have turned 18. What does go away are the supports that have assisted individuals to lead as ordinary a life as possible.

1410

By definition in the new legislation, a developmental disability must be acquired before age 18. This is a prime example of why the legislation is bad.

Our assistant deputy minister spoke in his deputation of the need for societal change. In the words of a very wise woman, a well-known advocate in Ontario, Judith Snow, "Society will change when I am in it."

When individuals leave the school system at 21, they have lost all of their supports because the system is so underfunded. How can society change when some of our citizens are stuck at home on the couch with no supports available to assist them to participate in their chosen community?

For many years now, developmental services has been based on the welfare model, and you've been hearing this over and over and over again. This model negatively impacts people. It also negatively impacts their family, and it negatively impacts Ontario. For true transformation to take place, the model must change to one that provides for economic growth.

When people with developmental disabilities leave the school system, they lose all sorts of supports. That's a significant loss, and there's a significant loss for the family: a loss of income, a loss of pensionable income, for the parent who must stay home with that person. That income is already woefully inadequate for individuals. Individuals can get OSDP, but we know that that income is woefully inadequate for people with developmental disabilities.

There's a psychological toll to primary caregivers in Ontario who are providing care 24/7, as Dalton McGuinty said, 365 days of the year, to support their adult children. FAO hears this from single parents, from very senior parents, and from many parents now who are currently supporting elderly parents.

Our society assists to provide intense care for a child with special needs because we recognize the responsibility of society as a whole to care for our future citizens. That is why the Ministry of Community and Social Services has programs to assist those children, and why Special Services at Home exists to provide that extra support. It's absolutely imperative that our society continue to support children into adulthood and that we don't have a break in that support. The need is there in childhood and the need continues on through adulthood. Contrary to an unspoken belief, those needs do not miraculously disappear just because somebody has an 18th birthday. It's not a very good birthday present for anyone in Ontario.

For almost 25 years, FAO and our affiliates have continuously asked the ministry to allocate 25% of new funding to individualized approaches. This has not

happened. Currently, only 9% of the \$1.7-billion budget is directed to individualized approaches. The remaining 91% is directed to transfer payment agencies for programs that support a significant minority of people. Ontario continues to invest the majority of funding into a minority of its citizens with developmental disabilities to continue to participate mostly in segregated and congregated settings. Ontario continues to talk the talk of social inclusion but is clearly not walking the talk.

The current system of supports is heavily dependent on families yet does little to acknowledge that dependency, little to ensure that primary caregivers stay healthy or to address the financial impact of caregiving on citizens in this province. It's estimated that an average family provides the equivalent of \$80,000 per year in unpaid supports—you heard from a well-spoken mom earlier about the cost in supports for a young person with autism—yet there's no recognition for that financial investment. Through the family response to the Ombudsman's office investigation—I know well over 1,000 families have responded to that—it has become painfully evident that as the system operationalizes its new policies, this vital piece, this support to family caregivers, is missing.

For true transformation to take place, it's imperative that services no longer be based on a welfare model but be recognized as an avenue for economic growth worthy of financial stimulus. Resources invested in the individual not only provide for the opportunity for meaningful community participation; they also provide income for people and an opportunity for parents to be wage earners and opportunities for parents to contribute to our pension plan. The individual, through community participation, becomes a consumer and adds to the economy of a vibrant Ontario. Now there are four Ontario citizens adding to our economy and adding to our community.

For people without developmental disabilities, relationships almost naturally occur. For people with developmental disabilities, because of attitudinal barriers, the building of relationships sometimes can take some intentional effort. Over time, the breaking down of attitudinal barriers will occur. This is a paradigm shift that MCSS has identified as a key element in their transformation journey. However, if society is unable to discard the assumption that people with developmental disabilities lack capacity or are unable to participate or need protection or should be hidden away, this will never change. The breaking down of these barriers requires Ontario to walk the walk: a true commitment and a significant financial investment in the developmental services sector.

The system is built and continues to be built on supporting a system instead of supporting people, supporting the individual. In reading the presentations from various ministries, it is apparent that, despite claims of inter-ministerial co-operation, this clearly is not happening. MCSS does not appear to know how many young people with developmental disabilities are living in long-term-care facilities. How can that be? People receiving services as a child need to reapply for services as an adult.

The list goes on and on. The system has become very good at dissuading people from even applying because there is no hope of receiving support, service, and certainly not funding.

Family Alliance is calling for action and rapid change to the current developmental services system based on human rights and principles of true citizenship and social inclusion and self-determination, including significant and effective inter-ministerial collaboration and a substantial investment of financial resources, specifically targeted to individualized funding and individualized approaches. This must be equitable, portable and inclusive of independent facilitation and planning so as to meet the needs of Ontarians living with developmental disabilities.

Furthermore, FAO believes that any support system must be based on essential human values. FAO recommends that developmental services adopt a set of guiding principles according to which services should be established and measured. These principles are: human rights, social inclusion, self-determination and citizenship. With these principles, not only will the lives of a person with a developmental disability be enriched; so too will the lives of the family and the community become stronger. Only by having an individual actively participate in the community and sharing their gifts and sharing their talents with others will those attitudinal barriers change. Then we will see that paradigm shift in society that MCSS claims to envision.

I'd like to identify some of the current problems. There are many problems with the system as transformation continues to very, very slowly roll out. We're just commenting on a few of the most glaring, and you've certainly heard this one: Developmental services is a discretionary program. By definition, according to Webster, "discretionary" is an adjective meaning "available to be used when and how you decide" or "used when necessary." In this situation, funding is available depending on when and how someone at the ministry decides to allocate it or decides when it is necessary.

With a discretionary program, one can turn a blind eye to the needs of individuals, citing inability to provide services or not enough resources or no clear data or no knowledge of real need. An entitlement to services evens the playing field. Most importantly, it identifies the value of the person. Everyone deemed eligible will receive the level of services based on their need.

1420

Premier Wynne, in her apology to the people who suffered in Huronia Regional Centre, said, "A government's responsibility is to care for its people, to make sure they are protected and safe...."

"In Ontario, all individuals deserve our support, our respect and our care."

The duty to support our most vulnerable is our government's most important responsibility.

We have also heard about block funding. I know we're all saying the same things. This is really good. We've got themes happening. As we said earlier, the majority of funding is currently allocated to transfer payment agen-

cies with which the agencies develop programs and residential supports. The system continues to build to support the old system instead of being developed to support the individual and move to personalized budgets, direct funding, individualized funding. There are lots of ways we can describe that. FAO prefers personalized budgets. We'll empower the individual and their support network to seek out the best supports for that funding that's allocated. This will serve as a catalyst for service delivery agencies to respond to the needs. There's evidence of that around the world. We have international evidence that has been shared with government over and over again. It will encourage service organizations to find ways to individualize their supports, to move forward and to change and move towards social inclusion.

DSO: We have heard from families that DSO is just an added layer of bureaucracy that has created a barrier to access supports and services. DSO is also creating a barrier between the needs of families and individuals and real action to prevent crisis in the community. The assistant deputy minister describes one of the key roles of the DSO as to provide information to individuals of other available services in their community, such as health care and community programs. He goes on to say that DSOs have added significant value to the system and are achieving a very important purpose. I have to tell you, families across the province are saying, "What is the significant value to the person? What is this value to the family?" Nobody is feeling that. We're 10 years in.

This single access point has morphed into a multi-level process that actually prevents people from seeking the help from some lovely community organizations, like Peter Dill's, that have been there for families for 30 years or more. Our members tell us that the DSO staff are not responsive. We're hearing that more now because I think they're overwhelmed. I don't know how long you could hear all these terrible stories from families and not just get desensitized from it.

You've also heard about the welfare model. Developmental services has been based on a welfare or charity model of providing supports and services. It's time to change that model and change it to a model that's rooted in economic growth for Ontario and looks towards authentic social inclusion for people.

The application process and assessment are lots of times being felt as very intrusive for families, and they're purely deficit-based. Our families feel—and it might not be because of the assessment; it might be because they're so desperate and they're so much in crisis—like they're just on a race to the bottom of a list.

Independent facilitation and planning provides an opportunity to move forward with a real actionable plan based on strengths and choice and control of the individual and their support network. Providing funding and services and supports to individuals and their families enables ordinary life to happen. Ordinary life happening is good for Ontario.

The Chair (Mrs. Laura Albanese): I just have to let you know that you're about 30 seconds away from the end of the time. I want to give you the chance to wrap up.

Ms. Cindy Mitchell: All right. I just have to—the lack of trust in Ontario really saddens FAO. We heard a little bit of this coming forth at this table where it was said that people fear direct funding and that they thought it might not be politically correct, that the money might not go where it's intended. Twenty-five years of direct funding through SSAH cannot be wrong. Our auditor cannot be wrong. Christopher Wrigley, a 37-year-old man from Meaford, Ontario, said he's not wrong and his mom is not wrong in regard to exceptional management skills. He said, "I've made a really good effort to live on provincial allowances and my mother is an excellent manager, but has made huge sacrifices for me to live a stimulating life in my community."

The Chair (Mrs. Laura Albanese): And I'm sorry; at this point I have to stop the presentation, because we have a long list of people, and otherwise everyone would fall behind. But we are thankful that you gave us the whole package, and we will make sure to read it carefully. I can assure you that all the members of the committee will be taking this in close consideration.

Ms. Cindy Mitchell: Okay. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you for your passionate presentation.

Ms. Cindy Mitchell: After sitting here for one hour, everyone's saying the same thing, over and over and over again.

The Chair (Mrs. Laura Albanese): But everybody adds something new, a twist that is new, and that is important for us. Thank you very much, and thank you, Karen.

Ms. Karen Inwood: You're welcome.

The Chair (Mrs. Laura Albanese): Thank you again for distributing these to us.

FAMILIES MATTER CO-OPERATIVE

The Chair (Mrs. Laura Albanese): We'll now hear from Families Matter Co-operative. We'll ask the executive director, Miriam Fry, to come forward. I know you've been in the audience as well, and I'm sure you know how this works by now.

Ms. Miriam Fry: For sure. Our presentation will be handled by Nancy Brodie, who is our past president, but I'm available for questions.

Ms. Nancy Brodie: I'm Nancy Brodie. I'm the past president of Families Matter Co-op, and I'm the mother of a 30-year-old young woman with a developmental disability, although she would say that she has an intellectual disability—here we go with terminology. We're also here with Sharon Edwards, who is the president of Families Matter Co-op.

That's a tricky name. People always get it a little bit wrong: Family Matters. Anyway, we say, "Families Matter." Families are important.

We are an Ottawa-based, member-driven, not-for-profit co-operative, so a little different model from some of the organizations that you may have heard from. We were established by families and friends of people with

developmental disabilities to empower and strengthen families to help support and have their family member have a really good life in the community. The way we try to do this is by connecting families with each other and making sure they have the information and the resources they need to really make an impact on their lives and the lives of their family member.

We try to raise awareness of the challenges facing families, so we're really glad to have the opportunity to be here today to do that.

We gave you a long list of some of the activities we undertake, but there are a couple of things I wanted to highlight. We have created new affordable housing in our community by working with developers and service agencies, and we now have 14 people living in affordable housing with some kind of support. It was partly through the partnership with the developers and also through the innovative housing funding that Bonnie Dinning mentioned benefitting from.

We have also created a social enterprise called Laundries Matter co-op—

Ms. Miriam Fry: No, it's actually Laundry Matters.

Ms. Nancy Brodie: Oh, Laundry Matters co-op. Gee, I get it mixed up too. We currently employ—

Ms. Miriam Fry: We employ eight individuals part-time, in co-operation with a long-term chronic care hospital. We do the personal laundry for approximately two dozen people who don't have family to rely on.

They earn money every week. Because of their intellectual or developmental disability, they work in teams, in coordination with their day program, but they are very proud of the work that they do, and they do a very, very good job. They have been doing this now for over a year, and we are slowly growing our business and hoping to start a second business.

Ms. Nancy Brodie: A couple of other activities that we're involved in: For many years, we've been involved in a transition fair in Ottawa for people in the school system who are reaching that age of transition and their families who desperately need information. Rather than have them go out to all the organizations, we decided to try to bring all the organizations together. We've also run a workshop called Beyond Graduation, where we bring together families and students with a developmental disability and help them try to make a plan for the future.

1430

These are some concrete activities we're involved in, and virtually all of them are in partnership with some other organization in the community. We really try to act as a catalyst.

We'd like to talk about some of the things we think are working well, some of our concerns and then some of our suggestions for improvement.

What's working well? We have ODSP. It's an entitlement. A lot of people have been talking about the need for entitlements. Well, that's one program we have. There have been good improvements to ODSP. There has been an increase in the rates and a reduction in the clawback of employment income, which has made a huge

difference to a large number of people who have part-time, minimum-wage jobs. They now have double the income that they had before because it's not being clawed back.

We look, as family members, at the Disability Tax Credit, which is a federal program but it's something that benefits many individuals and families. Again, the federal initiative of the RDSP, but then the provincial ability to integrate that with ODSP is very well received by our members and many families of people with disabilities. We also look upon something like a Henson trust as a building block when parents are trying to build a safety net for their children. Parents are trying to do their best to plan for the financial future of their children, and all these programs help them do that.

If we look at some of the concerns, and I think a lot of these you've heard from many other organizations, one that we see particularly is the difficulty families have navigating the system. Miriam talks every day to families; we meet them at our Beyond Graduation workshop; our members encounter them in the community. They don't know what they need. They're not aware that they can ask for assistance and they need advice on how to utilize the few services that are available. These needs are particularly strong at times of transition, and that's transition from the school system into adulthood and also transition into old age, and I don't think we've seen all the concerns there. They're just going to be hitting us more and more. So one of our roles is helping families navigate that system.

The concerns about lack of services or lack of capacity in the service sector: Miriam has come up with some figures in the Ottawa area. There are about 900 people on the wait-list for day programs and 900 people waiting for residential support. You've seen the provincial figures. Just looking at it from the Ottawa area, these are pretty huge numbers.

The way we see the DSO process evolving is, yes, there is a rigorous assessment process which should bring us equity across the province. But there's a waiting list even for that assessment process, and there are no services available at the end of the process that match the needs that are identified. When a child leaves school, families often bear the full responsibility for support, and this is a burden, not just on the individual who doesn't have the support and who isn't living a full life in the community, but it's also a burden on the family members and often the extended family.

Finally, I'd like to talk about lack of support for innovative solutions. Many families are in a position where they can provide some financial help, but government policies don't always encourage that. Many families would like to have individualized funding. They have lots of ideas of what they think is best for their family member and how they could best meet those needs, but, again, the demands for individualized funding are growing; the waiting lists for the Passport program continue to grow.

We have many families that are interested in supporting home ownership for their child, and they may have some financial resources to enable them to do that, but

how do they get the supports that they need in the home that they may be able to afford to buy? Funding those supports and sustaining them over time is very difficult.

We really look forward to the transformation of the developmental services sector, but from our point of view, it seems to really have stalled, that the assessments are slowly being done, and meanwhile there are many things that seem to be on hold.

Another principle that's really key for Families Matter Co-op is the right of individuals and families to choose the supports and services that best suit their individual needs. We know that there needs to be a strong service support sector. We know also that a lot of families would like to have individualized funding and could do many creative things. So we'd like to see MCSS continue to work on options for more direct funding, and partner with agencies to create individualized support. We would really like to see supports be more portable. But we desperately need a better overall system of supports, to make good choices possible.

I think you may have heard this from a few other presenters. There are some individuals who have very complex needs and who need a lot of support, a lot of services—multiple disabilities; families who are aging or under stress. So we need a strong support service system, and it should be person-centred and it should match not only the needs of the people, the individuals, that come out through an assessment, but also their dreams: what they want to achieve and where they see themselves in the world, in the community. But how do we make improvements in this area?

I think Miriam was a member of the Housing Study Group of the provincial partnership table, and one approach they took was to try to come up with some clear, achievable targets in the supported housing area. We think that is maybe a practical approach, something that can maybe achieve some results, and maybe that targeted approach in other areas would work as well.

We would really like to see different ministries working together. We feel that there is a lot of research and approaches that have been taken in the health care sector, in the mental health sector, that have achieved results. Can we make that same kind of concerted effort in the disability services sector to try to make some concrete steps forward? We would encourage action on the action plan of the report of the Housing Study Group.

There are many people who need a little, and a little can make a huge difference. With a little help from government, families can help a lot. Some of the ideas we have, that we think wouldn't cost governments a lot of money, wouldn't require huge extra investments, are:

- Increase the flexibility in ODSP.

- Increase the amount an individual can receive as a gift and have in a bank account without penalty.

- Relax the rules related to shared living. I've investigated this area, thinking of my daughter's future. I thought, really, that the regulations around who can live together, and at what stage of living together is your ODSP going to be reduced, just don't reflect reality or the way people live these days. Why should people who

decide to live together end up with fewer resources when, actually, they're trying to build a better life?

—Maybe we should consider introducing a support component to ODSP. Maybe this is a mechanism to extend the entitlement aspect to the support area.

The Disability Tax Credit is something that hasn't increased for quite a while. Maybe that's something that could be increased. It could give some more money in the hands of families that they could use to make a big difference.

1440

Some other areas where we have some suggestions: this whole area of supporting families to navigate the system. Give support to organizations like Families Matter Co-op that can provide this support. Again, this is something that's happening in the mental health sector with patient navigators. I think it's something that we need in the disability services sector as well.

We've heard about the DSO assessments and the need for many families to have to go back and get a psych assessment that they never had in the past or that isn't up to date. Well, if this is part of the assessment process, then there should be some money made available for families to get those assessments that are needed. Money should not be a barrier to the assessment process, surely.

There should be more flexibility overall in the allocation and reallocation of resources to encourage grassroots creativity, and I think you've probably heard many different areas of creativity and ideas of how that can be done. We see that there should be more focus on co-ordination and support in transition stages, especially into adulthood. There are some models we've heard of where school boards actually have a transition coordinator at the board level and they really put a focus on that. Maybe this is a model that should be more widely followed. One of our members who works in the school system said, "You need to support that transition, not at age 17, but it needs to be something that starts much earlier." Maybe it could be through peer relationships with other families who have gone through the process in recent years.

As I mentioned earlier, we think it's really important to engage broader government expertise beyond the Ministry of Community and Social Services to address the complex problems that many people with developmental disabilities have. So we need to look at housing: When we worked with developers to establish places for people with developmental disabilities in affordable housing, this was hugely innovative. They said, "Oh, we set up spaces for people with physical disabilities," but they had never considered having spaces for people with developmental disabilities in housing co-ops or other models of affordable housing. So let's look at the housing and affordable housing strategies, and include people with developmental disabilities. Again, the health care system is—you've heard about how there needs to be more education there, but, again, I think maybe we can also learn from some of the progress made in the health care system.

That's the end of our presentation, and we'd really welcome the opportunity to answer any questions from our experience.

The Chair (Mrs. Laura Albanese): We really have time for just a brief, brief comment from each party. We already have the next presenter via teleconference ready to go. Christine?

Mrs. Christine Elliott: Thank you, Chair. I will be brief. Congratulations on all of the innovation you're doing with very limited resources. I would just be particularly interested in some of the innovative housing solutions you've developed and learning more about how you've worked with developers in order to create those housing opportunities. So if you have any written material you could provide us with or perhaps we could have a conversation offline, I think that would be really helpful to the committee. Thank you very much for being here today.

The Chair (Mrs. Laura Albanese): Ms. Taylor.

Miss Monique Taylor: I would also be interested in seeing that model, and I'm just curious—a yes or no answer—did you have problems with the ministry when you were doing these housing initiatives?

Ms. Nancy Brodie: Yes and no.

Miss Monique Taylor: So those are the kind of issues that we need to hear. We need to know where things went wrong and where we need to further support those initiatives because it's definitely something that we need to be doing, moving forward. Thank you so much for all the work that you're doing.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair. I also really felt that this was just a trove of information for us as we're getting into our drafting the report and just very clearly presented what is working well, the things that are helping to support the system and then, of course, the areas that need improvement. So I want to thank you for taking the time to be here today to provide this input, and for the work that you are doing. I'm also looking forward to hearing more about social housing and how you are managing to get that message out to developers, who oftentimes have a different model that they're using. They're starting to see the benefits of doing that, and I think that would be a very interesting thing for us to hear.

The Chair (Mrs. Laura Albanese): Thank you very much.

Ms. Nancy Brodie: Thank you.

Ms. Miriam Fry: Thank you.

The Chair (Mrs. Laura Albanese): If you could put anything in writing, as all the members have suggested, that would really be helpful to us. Thank you.

MS. KARIN STEINER

The Chair (Mrs. Laura Albanese): Now we're joined by Karin Steiner via teleconference. Hello? Good afternoon, Karin.

Ms. Karin Steiner: Yes, hello. Thank you very much for allowing me to follow up on my written submission to the committee. I really appreciate the teleconferencing

option, because I live about 200 kilometres from Ottawa and about 300 kilometres from Toronto.

The Chair (Mrs. Laura Albanese): So we will allow you to make your presentation.

Ms. Karin Steiner: I'm contacting you as one individual who has been trying to understand how to navigate the DSO system for about seven years now, ever since my son Nicolas, who is an adult with severe autism, transitioned from school to home.

My letter dated December 31, 2013, asked the committee to address the urgent need for policy-makers to provide direct, individualized residential support options for families or caregivers of adults with developmental disabilities. My letter included two attachments, A and B, comprising the letter I wrote in January 2013 to Ombudsman Marin and a series of exchanges amongst myself; my MPP, Mr. Hillier; Minister McMeekin; and the southeastern Ontario region's MCSS officials.

Although my letter to Ombudsman Marin—attachment A in my letter to you—focused on a range of what I perceive to be systemic problems, specifically problems with the new intake process, the new database and the issuance of percentile scores to service needs that are not clearly linked to service provision or funding, today I will focus only on one issue, given the short time frame. That issue is the urgent need for individualized residential supports that could be managed by caregivers, or by caregivers working closely with a case management agency.

In attachment B of my letter to you—that's the letter of May 17, 2013, the last letter in the series. It's from Josephine Fuller's office, and it states, "Currently the Passport Program is the only ministry-funded program that supports direct funding. Recipients of Passport purchase community participation supports and/or respite care. Presently there is no direct funding program to purchase residential service."

I have to admit that I was really quite surprised to read that statement, given that both ADSS reports on my son—one in 2012, and a revised report in 2013—included the following categories of residential supports under section 4, "Services and supports," on page 22 from the 2013 report:

"Service type 1

"Which one of the following MCSS-funded residential supports is currently provided?

"—supported independent living

"—group home

"—host family home

"—individual residential model

"—specialized accommodation

"—outside paid resource

"—other."

In my son's case, the report indicates accurately that no MCSS-funded residential supports are currently being provided, yet there's quite a wide range of possible supports, according to that list that I just read. One problem here is that, on the one hand, I'm told that no direct individual funding options currently exist for residential

supports, yet the individual residential model is listed as a possibility in my son's ADSS reports.

My letter to Ombudsman Marin flagged the need to examine the IRM—I think that's the acronym for individualized residential model—as a possible form of direct funding. My understanding is that caregivers or agencies applied for a grant for individualized funding for innovative residential plans, and those who got the grant were given funding in a way that could be construed as direct support to individuals. In 2007, 89 individuals were apparently living as part of an IRM arrangement in Ontario, according to a summary report by Carver and Associates, dated July 2009, called *A Home That's Right for Me*.

1450

I'd like to know more about how those 89 people have fared over the past seven years and why newcomers to the DSO have not had opportunities to apply for IRM funding. Also, how many people are living in so-called specialized accommodation, and what does that mean? How many benefit from the outside paid resource or other residential supports? Are these categories not possible direct support options?

Additional questions from me and my son are: How does one qualify for individualized residential supports? Does my son Nicolas's score in the 84th percentile on the SIS qualify him for individualized residential supports? If so, if he does qualify, why hasn't there been any movement to provide the supports he needs? He entered the new database in 2011. If he does not qualify, why did I bother sitting through a grueling five-hour-long interview process to be included in the new database and why have I had to invest so much time and effort just to have very basic questions answered?

In short, as I stated in my letter to your committee, I'm very, very frustrated as a caregiver who is doing her level best to work within the various systems that have emerged over time, but I'm deeply concerned that the new DSO bureaucracy, its costs and opaque practices, will obliterate the possibility to serve families like mine with legitimate requests for appropriate supports.

In closing, my main concern each and every day is what will happen to my only child, Nicolas, when something happens to me. I have not yet found a reassuring answer either from the DSO, my case management agency or MCSS officials in southeastern Ontario, and that's why I'm appealing directly to MCSS in Toronto via this talk with your select committee.

That wraps up my remarks, and I certainly welcome any questions you have about my situation.

The Chair (Mrs. Laura Albanese): Karin, before I pass it over for any questions, where exactly are you calling from? You did mention that it was 200 kilometres from Ottawa, 300 from Toronto.

Ms. Karin Steiner: I'm in Hartington, which is 40 kilometres north of Kingston, Ontario.

The Chair (Mrs. Laura Albanese): Okay. Now, you've illustrated quite well the difficulties in navigating the system. I will offer my colleagues a possibility to ask

more questions. At the same time, through this committee, we are looking at the concerns in a general way. We're not addressing a specific case, not to say that—that could certainly be forwarded to the ministry. But as a committee, I just wanted to make the premise that we're not doing that as a whole, as a committee, because we're trying to address the gaps that we see in the system as a whole. We can't really address a single concern in itself. That is not the mandate of the committee. But having said that, we will make sure that your specific concerns are forwarded to the ministry.

We will now have Ms. DiNovo comment and ask any questions she may have.

Ms. Cheri DiNovo: Thank you, Karin, very much for your articulate delivery of concerns. The first thing I'd like to say is that you're not alone. We're hearing the same thing from just about every parent across Ontario. Certainly, it seems to us on this side, in the New Democratic Party, that the DSO is not functioning. Any organization that all it does is put parents through assessments and delivers wait-lists as a result of those assessments, not services, is not functioning. The situation is clearly in crisis. You're experiencing that crisis, and for that we are deeply saddened. It's certainly true that your child—and you—has every right to be treated the same way as every other child in every other family that doesn't happen to have a developmental disability, and that means equal access to housing, to education, to health care—everything you should need. Really, that's all I can say.

I would suggest, though, to meet with your MPP because, certainly, if you were living in my riding, I know I and my staff would try to go to bat for you with MCSS, and I think that is our role. I don't think that's beyond our role. So I would suggest that you do that. You'll probably hear frustration from your MPP through that process, but you might actually get some results as well.

Again, thank you so much for your testimony before us, and our heart goes out to you.

Ms. Karin Steiner: Thank you, but did you receive my written communication?

The Chair (Mrs. Laura Albanese): We have been travelling, as you know, in the last few days, but we do have your written communication.

Ms. Karin Steiner: Okay.

The Chair (Mrs. Laura Albanese): We will be sifting through all the written communication for sure. Rest assured, we will be doing that.

Ms. Karin Steiner: I ask that question because attachment B of my communication actually includes one letter written by my MPP to Minister McMeekin, as a result of the letter I wrote to him. I did not receive an answer from the minister, but I did get a response from Josephine Fuller, who's the director of southeastern Ontario's regional branch of MCSS. We've had a couple of communications and, again, I found those communications uninformative, and there has not been any help.

Ms. Cheri DiNovo: We hear you. Thank you.

The Chair (Mrs. Laura Albanese): I will ask Mitzie Hunter, who is also the parliamentary assistant to the minister, to say a few words and to address this.

Ms. Karin Steiner: Thank you.

Ms. Mitzie Hunter: Thank you, Madam Chair. Hello, Ms. Steiner.

Ms. Karin Steiner: Yes.

Ms. Mitzie Hunter: We definitely have heard your case and your concerns. As the Chair has said, we'll ensure that that gets back so that the ministry can do its follow-up. I think that's important that we do that.

I was wondering if you would be able to share your perspective, from a community basis, on just what you're experiencing as a parent. You mentioned this is your only child and that you have some concerns. Today we talked quite a bit about building an inclusive community and a sense of belonging for people with developmental disabilities. I think that that's something we have heard and seen through our travels through this select committee. So I was just wondering if you could share what you're experiencing for your child from your community perspective.

Ms. Karin Steiner: Thank you for the invitation to speak to this issue. When my son graduated from high school in 2007, I mentioned he graduated from school to home, because there were no supports available to him. Where we're located in Ontario, just north of Kingston, we are caught between agency services. There are services, say, day programming services, in Kingston and there are some available in Sharbot Lake, north of us. So where we live, never the twain shall meet.

As a result, I actually started a non-profit charitable organization here in South Frontenac township called New Leaf Link, which has a website: www.newleaflink.ca. The program that I started—because my background is in education—is an inclusive program that brings adults with developmental disabilities together into meaningful activities. It is a day program. We have an arts program and we've got a healthy living program, as part of New Leaf Link's offerings.

I've been working very hard to create opportunities for my son in our home community, because it is a very good place to live. I think living out in the country has been quite therapeutic for Nicolas, and he has had the opportunity to build relationships with people over time. A very key element of autism is the social realm and the difficulty in the social domain, so the long-term relationships are important ones to hang on to. Some of his friends from high school are part of New Leaf Link, and we do get new students coming to the program each year.

1500

We've tried to work, as a community, from the ground up. I spearheaded the initiative along with some other family members with sons and daughters, who have come together. In that sense, I think we have created a place where people feel that they belong and want to continue to grow together.

The Chair (Mrs. Laura Albanese): Thank you—

Ms. Karin Steiner: I've worked very hard to try to create opportunities too, and I'm willing to work with

MCSS to try to create opportunities now for residential supports, because that's the next thing for me, in my thinking. I've tried to pave the way for some daytime supports, but now the residential piece is the missing piece, and we definitely need supports in that realm.

The Chair (Mrs. Laura Albanese): Okay. Ms. Steiner, I'm going to pass it on to Ms. Jones for other questions.

Ms. Sylvia Jones: Karin, I think I remember you presenting to our committee when we were studying Bill 77.

Ms. Karin Steiner: Yes. Yes, Sylvia.

Ms. Sylvia Jones: Yes. Thank you for your continued advocacy. You're sort of reinforcing my belief—and tell me if I'm putting words in your mouth—that, depending on where our children are, we need different services; we need different opportunities; we need different supports. The fact is that you started New Leaf when you saw Nicolas needing some additional challenges, and now you're looking at the residential component.

Can you share with the committee whether that is what you have seen locally, or is there another way you would describe it?

Ms. Karin Steiner: No. I think you describe it well, Sylvia. Especially in rural areas—there are a different set of challenges in rural areas, and also with different disability groups. People with autism, for instance, are more sort of individualistic. I'm not certain that the DSO understands that there might be major differences across different types of groups in the system—

Ms. Sylvia Jones: You're being kind, Karin.

Ms. Karin Steiner: That's certainly my belief, that it isn't a one-size-fits-all model that's going to work. That's why I'm very interested in the individualized residential model, or some other innovative, individualized model for residential supports. I don't think the DSO recognizes that.

I see systems thinking versus people thinking, or—I'm not sure. Well, certainly it's not a very humanitarian perspective that comes out of the systems that have been foisted upon us. I would really like to see your committee ask some questions about the validity of the current system that has been brought in and also, who's benefitting from the DSO and its new protocols?

Ms. Sylvia Jones: Rest assured, we're doing it.

Ms. Karin Steiner: Okay, great.

Ms. Sylvia Jones: Thank you very much, Karin.

The Chair (Mrs. Laura Albanese): Thank you, and have a good afternoon. Thank you so much.

Ms. Karin Steiner: Okay. Thank you.

MS. LINDA NILSON-ROGERS

The Chair (Mrs. Laura Albanese): We will now call Linda Nilson-Rogers to come forward and present to our committee. Hello, Linda.

Ms. Linda Nilson-Rogers: Hello.

The Chair (Mrs. Laura Albanese): Good afternoon, and welcome.

Ms. Linda Nilson-Rogers: Thank you. My name is Linda Nilson-Rogers. I'm thankful to be able to present to the committee today as Sarah's mother. Sarah will be 29 years old this year. She lives in her own apartment in Almonte, Ontario.

Sarah's road to freedom and independence has been achieved by vision, hard work, frustration, persistence and determination to live in her community with the support she needs and deserves. This is Sarah's story of how we got to where we are today and what is still required.

When Sarah was young, it was important to me that she was integrated with her peers in the regular school system. It was also important that she was in her community and participated in activities that all children her age enjoyed. Her early years were important because they set the foundation for her to be accepted and appreciated for her gifts, strengths and contribution.

In June 2006, we had a setback. I injured my back and was unable to provide the care that Sarah required due to neurosurgery, leaving me with limited mobility. During that period of time, Sarah was receiving respite support from a group home which was operated by an organization in Almonte, the Mills. She was also receiving Special Services at Home funding. When she went into the group home full time, she lost that SSAH funding. My illness was unexpected, so it was difficult for me to think straight. I did not realize the full impact that placement in a traditional group home would have on Sarah and myself with regard to freedom of choice and individuality. The loss of SSAH funding, which is now called Passport adult respite, has been a stumbling block to us today in trying to build a life for Sarah in her community.

After Sarah had been in the group home for a while and I was feeling better, I knew this was not where I wanted to see Sarah for the rest of her life. As Sarah's mother, I knew we had to take steps to move her forward in her life. I wanted her to move out of the group home and have supported independent living, SIL, support in the community.

The pressure for change has always come from me to move forward with Sarah's life, teach her new things and help her be more independent. I found the first apartment and made arrangements with the landlord. We agreed that Sarah would share the apartment with another individual. It worked for a while, but the other individual's situation changed and he had to move back to the group home.

I found another opportunity, which lasted about a year, but the person whose parent owned the house decided she wanted changes for her daughter and Sarah had to move out.

Sarah moved into her own apartment in Almonte in January 2013, and the Mills was providing 16 hours of support weekly; that would be SIL support. When the original proposal was submitted in 2006, the Mills' proposal for Sarah was 35 hours of residential support, which is what she would require according to them to live in a group home. I feel she required more than 16 hours of SIL because I was providing a lot of natural

support to ensure her independent situation was working. What we wanted for Sarah was more creative support and what we were getting was an extension of group home support. There was considerable inconsistency and changes in staff. There wasn't a flow to Sarah's life. Her home life was also being controlled by "shifts." Sarah's life was not controlled or directed by Sarah.

Over a three-year period, with much advocacy on my part, there were some improvements, but I always felt there was resentment, impatience and lack of understanding in what the dream for Sarah's life was in the future. The organization is unionized, which also created additional complications and inflexibility of hours. Sarah's life with respect to her home and individuality in her home were contingent on too many external forces.

I am in my sixties and have experienced how health issues can impact the care you are able to give your child. Although Sarah lived in her own apartment, I spent a large number of hours creating and modifying things in her home to make it work for her and, at the same time, enable her to do more things herself. My biggest fear with the type of SIL support she was receiving was that when I am no longer in the picture, the vision that Sarah and I have for her life will fade and she will be redirected to a group living situation, as it is easier for an organization like the Mills to monitor and control. It was even suggested to me by a ministry official that if Sarah needed more support that perhaps she should move back into a group home. That was a wake-up call for me.

I am persistent and, as Sarah's mother and a long-time advocate for her, I know exactly what she needs to have a fulfilled, meaningful and safe life in her community. I had a concrete plan and ideas. I kept sharing my ideas and kept having meetings with the Mills, and just recently a miracle happened. The Mills must have decided that it would work better for Sarah if they let another organization provide SIL support to her.

Now Sarah is receiving SIL support from the organization that provides her with job activities and various day supports. It is also an organization in the county of Lanark, Lanark County Support Services. They provide support in four towns in the county. LCSS is an organization that engages families and empowers them. They don't take offence to my ideas, and we work together. Having this change makes me feel like a ton of bricks has been lifted off my shoulders.

1510

To put the difference in a nutshell: Sarah's life flows; it is not fragmented. Support is more personal, reliable and consistent. Sarah is the captain of her own life. Sarah is directing the support she requires. We don't feel like we are getting the runaround; we are moving forward at last. When we talk to people, they really listen. There is an intrinsic comprehension of what our goals and vision are for the future. There's creativity and accountability to Sarah and her family. There is flexible and person-centred support.

There is one piece of the puzzle missing. This became even more apparent to me in December when I broke my

leg. I provide a considerable amount of natural support to Sarah. As I previously indicated, the traditional system approach eliminated a lot of freedom and choice. One of the vehicles to promote choice was individualized dollars through the former Special Services at Home Program, which has now become Passport funding for adults. My next step will be to advocate for additional flexible funding, as this component needs to be in place to support Sarah when I am no longer able to support her. For example, there is not flexibility in SIL dollars for unexpected health care, professional development days or closures. Right now, I do not get time off and I am fill-in support. Funding for new safeguards for these types of situations is not in place or available now.

I am an involved parent, and because of that I have seen a lot of upsetting things occur in systems over the years. What about people who have developmental disabilities who do not have families, good advocates, and can't speak for themselves? There are far too many organizations out there that are providing traditional supports that do not want to change or have incredible barriers and obstacles that prevent change. People with developmental disabilities and their families are suffering. I trust that the work of the Select Committee on Developmental Services will create change in the right direction.

Thank you for inviting families and individuals. We are far too often the stakeholders who are put aside when decisions are made.

Thank you very much for hearing me.

The Chair (Mrs. Laura Albanese): Thank you for sharing your story with us. It is the government's turn to start the questioning.

Ms. Mitzie Hunter: Thank you, Ms. Nilson-Rogers. I really appreciate the story. You've shared the story of Sarah's life, and thank you for sharing the photographs. Are those pictures in her current setting?

Ms. Linda Nilson-Rogers: Yes, they are. She has an upstairs-downstairs apartment with a washer and dryer. She does her own laundry. She does her housecleaning. Yes, she has some quality control there. She has a yard that she has to help maintain, raking leaves and shovelling snow. She's capable of a lot of things, but needs prompting. She always will need some support around food and preparation of food, that sort of thing, but she stays alone at night and is quite capable in a lot of instances. I think she's much happier than she has been for years, and that's the most important thing.

Ms. Mitzie Hunter: I think that's very good, that you have advocated for her so that she can live as full a life as possible to her fullest capability.

Ms. Linda Nilson-Rogers: I think we should all be able to do that.

Ms. Mitzie Hunter: Yes, I agree. Thank you.

The Chair (Mrs. Laura Albanese): Mr. MacLaren?
Interjection.

The Chair (Mrs. Laura Albanese): No, we're not done yet. It goes in a circle.

Ms. Linda Nilson-Rogers: I'm sorry. I'm very nervous.

The Chair (Mrs. Laura Albanese): Please do not be.

Mr. Jack MacLaren: Well, Mrs. Nilson, I would say to you that your daughter is a lucky person; she has a great mother. You've done a great job.

Ms. Linda Nilson-Rogers: Thank you.

Mr. Jack MacLaren: We know it hasn't been easy. We've heard a lot of people present to us and tell us about the difficulties that the system presents. As you pointed out, the system is very resistant to change, and that's something that this committee is certainly going to consider. A lot of people have spoken about independence; I guess patient-centred or person-centred would be a way to put it. What does Sarah want? What kind of future does Sarah have a right to and does she want? You've been a great advocate for her, and it wasn't easy. You've had a few little stumbling blocks where you had health problems that put you out of business for a while.

Ms. Linda Nilson-Rogers: The last stumbling block was December.

Mr. Jack MacLaren: Yes. At any rate, I'd say good on you. You've done a great job. You've identified a problem, and that's something that others have also mentioned to us, so we're aware of it as a committee and we'll certainly be taking that into huge consideration. Sarah's rights have to be first choice. I think we have to try to make change that will consider that, so thank you very much.

Ms. Linda Nilson-Rogers: Thank you.

Mr. Jack MacLaren: Oh, and by the way, Almonte is in my riding, so I am her MPP.

Ms. Linda Nilson-Rogers: Yes. I think there needs to be, with a lot of the larger agencies, especially from what I've seen, more accountability for results. There isn't enough.

Mr. Jack MacLaren: Yes.

The Chair (Mrs. Laura Albanese): Point taken. Ms. DiNovo?

Ms. Cheri DiNovo: Yes; thank you. It was a wonderful presentation. It was so good to hear a good story. Lanark County Support Services sounds like a very positive organization. Could you tell us a little bit more about them? I understand they operate in four counties. Who is in charge of them etc.?

Ms. Linda Nilson-Rogers: I deal with a lady named Leigh-Anne Giardino, who is the supervisor in Almonte. Debbie McEwen is actually supervisor of the area, and she works out of Smiths Falls.

I first found out about LCSS basically through a program they put on at high school called Transitions. They did weekly two-hour bouts of getting Sarah into a work placement, finding things for her to do. It was a really wonderful thing because she got used to going out into the workplace. Everyone—I'm not saying it because she's my daughter—likes working with Sarah. I believe they were instrumental in a lot of the things she does, getting her out and about in town and just ensuring that she wasn't left on her own to make mistakes that weren't righted.

Ms. Cheri DiNovo: Is it kind of a Community Living organization? I'm just wondering.

Ms. Linda Nilson-Rogers: They have a day program. Sarah—because I had the accident and had surgery, she ended up having five days a week in their day program, which has been really great. She has job placements, some of them paid, some of them volunteer, but she's always busy. They've been so supportive of her. It's just wonderful. I can't say enough about them.

Ms. Cheri DiNovo: Thank you. To my colleague.

Miss Monique Taylor: Great work with everything that you've been doing and making sure that Sarah is getting the life that she wants to live. That's absolutely so important. You've actually been the role model of what we're looking to put in, and that's a navigator. We're thinking that a navigator in a person's life could help make those transitions where it's necessary. When mom and dad aren't around or not able to make those—and to tell the story again and again and again—

Ms. Linda Nilson-Rogers: Yes.

Miss Monique Taylor: —of Sarah's life, that there will be something in place to make sure that there's consistency to the flow of Sarah's life. Great work. Thank you for everything that you're doing.

Direct funding is actually something that would work in your benefit.

Ms. Linda Nilson-Rogers: Yes, it would. It would work in Sarah's benefit.

Miss Monique Taylor: Thank you.

The Chair (Mrs. Laura Albanese): Thank you again for your dedication and your determination and for presenting to us this afternoon. Best of luck.

Ms. Linda Nilson-Rogers: Thank you so much for having me.

MRS. CORA NOLAN

The Chair (Mrs. Laura Albanese): We'll now call on Cora Nolan. Good afternoon, Cora.

Mrs. Cora Nolan: Good afternoon. My name is Cora Nolan, and this is a friend of mine, Joyce Rivington. She presented earlier today.

I live in the village of Franktown in the county of Lanark. My husband, Claude, and I have two children, Pauline and David. Our son, David, who will be 39 years old in March, has a developmental disability, limited speech, numerous medical challenges and needs supervision and support 24/7. This is a picture of David. He's actually smiling in it too.

David has always lived at home with us, and as aging parents we want to ensure security for his future when we are no longer alive.

David spent most of his school life in a segregated school. As a young child, David was in receipt of Special Services at Home funding, which gave us the first opportunity to purchase supports that would meet his specific needs. When leaving school at 21, the only option offered in our county was a segregated day program that offered traditional supports. We did try this, but David was very

unhappy. He did not want to attend, and this caused him frustration, anxiety and regression. It became very apparent that this did not meet his needs.

1520

We realized that if we wanted him to have a full, interesting and productive life, similar to what you and I experience, then we needed to design a personal plan for him that would meet his needs and lifestyle, based on his needs, interests, strengths and the skills necessary to function and be personally successful to the best of his abilities in his community.

In 2004, we developed a personal plan with a budget and began our quest to acquire funding to support it. We approached ministry personnel in the Kingston area office, and we're fortunate in that they were open-minded. They could see the benefits to David and acknowledged that this was a financially responsible approach to meeting his needs. We did receive some funding that allowed us to implement part of David's plan. This personalized, direct approach enables David to have a varied and interesting life. Quite frankly, it has not been an easy road to travel and there have been many stops, twists, turns and tears along the way. But it is amazing what a difference this approach has made, not only to David, but to our family as well. He is happy, enthusiastic and proud of himself and his accomplishments.

Individual direct funding is not a program, it is a lifestyle that is person-directed. We believe in this approach because it enhances quality of life through individualization for David. It promotes true choice. It respects his rights and encourages flexible opportunities and options. There is a true recognition of respect and dignity, and there is individuality, which ensures a better and more meaningful quality of life now and in the future. Individuals with disabilities have the same wants, needs, rights and expectations as anyone else.

David has come a long, long way from when doctors told us he would never walk or talk and advised placing him in the Rideau Regional Centre. He has faced challenges medically, personally and physically that would challenge any one of us. He has shown courage, determination and strength in trying situations, and has prevailed. He is happy, loved, cared for, and his strengths, needs, likes and dislikes are being met in a variety of unique and creative ways. Isn't that what most of us want for ourselves?

Our ultimate goal is to have adequate, annualized dollars to implement and support his entire personalized plan, and include cost-of-living allowance increases, to enable us to pay his support workers a reasonable salary.

In 2010, we built a home with accommodation for David to have his own space within our family home, and he is really enjoying this ownership. It also provides security and stability for his future. We are aging parents; this year my husband will be 71 and I will be 69. This past year was a wake-up call for us when my husband was diagnosed with cancer. It involved surgery, recovery and six months of chemotherapy. Quite a jolt, and it made us face the potential problems and the need to have

adequate and secure funding supports in place to provide stability and security for David. We are continuously stressed and worried that David's current funding will be cut or reduced. We go from year to year not knowing what processes or applications will be changed or required.

I realize that not everyone or every family wants to take the time to plan, implement and supervise an individual plan for their son or daughter, where you hire your own workers, self-administer funding, do record-keeping and all related paperwork. I acknowledge that it does require a great deal of time, but we consider it investing in David's future. We live with the results; therefore, we are going to ensure that his needs are met in a responsible way. I also know very few families in our county are being encouraged or supported in developing and using this approach to meet their sons' and daughters' needs.

Yet, parents and families who choose this approach are left out of the information loop. We are not advised about possible changes until decisions are already made. This select committee is a good example. We did not hear about it until mid-December, only by chance by a newsletter from a local parents group. I immediately phoned to request making a presentation to this committee in Ottawa.

Parents and families and individuals with developmental disabilities are the ultimate stakeholder. Professionals and governments come and go. Parents know their child best. They are the experts and ultimately live with the results. Therefore, it stands to reason that every parent wants what is best for their child..

In June 1996—that's 1996—a document entitled *In Unison: A Canadian Approach to Disability Issues*, a vision paper developed by the federal, provincial and territorial ministers responsible for social services, "sets out a blueprint for promoting the integration of persons with disabilities in Canada." It was reaffirmed in December 1997 "to make disability issues a collective priority in the pursuit of social policy renewal...." I feel that since that time, a great deal of time and money is spent spinning wheels and going in circles.

Some of my concerns, suggestions and recommendations: Invest in people and individuals, not systems or another level of government.

Stop putting individuals in boxes and assigning them numbers.

An individual requires and needs varying levels of support. No two people are exactly alike.

Supports must meet the needs that are necessary for a rich and meaningful quality of life with choices and flexibility.

Individualized plans must be developed by persons who know the individual well. Encourage families, who best know their family member's need, to develop the plan and attach a budget, with access to the funds to implement it. Otherwise, it's a waste of everyone's time.

The Ontario Disability Support Program funded by the ministry is an entitlement program for shelter, food and clothing for individuals with developmental disabilities, and it also needs to be increased.

Funding to provide support to individuals with developmental disabilities should be an entitlement, not a discretionary program.

Entitlement, meaning:

—same deal for everyone;

—to be active participants in society and do meaningful and productive activities of choice;

—to choose their own lifestyle, system of support and friends;

—to continue to learn and experience personal growth and development;

—to dignity and respect for human worth;

—to recognition that the individual is the key stakeholder in all decisions that affect their life. “No decision about me without me.”

In conclusion, I wish to thank you for the opportunity to tell our story and to express my opinions and beliefs. I would like to finish with this parable; it really says it all.

“Beyond Programs: A Parable

“In the beginning, there was placement, and lo, we were happy when it happened, as placement was not mandated for adults who happened to experience severe disabilities.

“And so, we said, this is good.

“And placements multiplied and filled the earth.

“And then, we said, let us make programs, which focus on serving clients. And clients were defined and labelled, and grouped according to their labels. And programs created services for each label, and state agencies developed unit costs for each service. And programs prospered and multiplied, and we said, this is very good.

“And as programs multiplied, a cry arose: Let us evaluate these programs to see how good they really are.

“And program evaluation, state regulations, quality assurance compliance plans and other program measures were created. And they filled volumes.

“And in those times, a person arose who was a client, but who was also a prophet, and said:

“‘I don’t want to be a client. I want to be a person.

“‘I don’t want a label. I want a name.

“‘I don’t want services. I want support and help.

“‘I don’t want residential placement. I want a home.

“‘I don’t want a day program. I want to do meaningful productive things.

“‘I don’t want to be ‘programmed’ all my life. I want to learn to do things I like, and go places which I like.

“‘I want to have fun, to enjoy life and have friends.

“‘I want the same opportunities as all of you: I want to be happy.’

“And there was a long silence. And lo, everyone realized that they must look beyond their programs. But they were troubled and they asked:

“‘How can we do this? Would not each person need their own unique program and system of support and his own individual measure of quality?’”

“And the prophet replied:

“‘Even as you say, so should it be done—just as you do for yourselves.’”

The Chair (Mrs. Laura Albanese): That’s beautiful.

1530

Mrs. Cora Nolan: I’ve included a copy of that in the package, and also a copy of the cover page for In Unison, which gives the information to get copies of it. That was 1996, and I know families were really excited when they saw that because we thought, well, there’s federal, provincial—they’re all going to work together here and we’re going to go someplace, and it didn’t go anywhere.

The Chair (Mrs. Laura Albanese): Well, we’re trying to work together now and to go places. I will now allow, is it Ms. Jones or anybody who would like to—Ms. Elliott.

Mrs. Christine Elliott: Thank you very much for bringing this parable to us. I think it really does say it all. It encapsulates all the concerns and frustrations that many people have been bringing to us. I guess all I can say is what we’re hoping to do in this committee is to work past that and to work past what happened in 1996 too with the Vision paper and really make something happen that’s going to be meaningful to families. But we certainly will take a look at this. Maybe it will give us some help going forward about what the thinking was at that time and help propose some solutions that are going to make a difference.

I’m certainly very happy for you, that you’ve been able to find some solutions for your son David, but you’re right: It’s because you and your family, as family members, have done so much as individuals. But we need to also be mindful of the fact that there are many families that don’t have those resources and aren’t able to do that, and so we want to make sure that everybody has the same opportunities. But congratulations on what you’ve been able to do for your son.

Mrs. Cora Nolan: I just got tired fighting with everybody, and nobody could seem to see what I wanted, so it was just easier to do it myself.

Mrs. Christine Elliott: Well done.

Mrs. Cora Nolan: With help from friends—lots of friends.

The Chair (Mrs. Laura Albanese): Miss Taylor.

Miss Monique Taylor: Hi. Good afternoon. Thank you so much for your presentation today and for taking the time to put a presentation together and to come and share it with us. It is so important that we hear from you and the trials and tribulations that you’ve gone through with David. Knowing that David has a good family and an advocate is so important, and we’ve been talking about that. We need to make sure that people have somebody to be able to guide them through our process and that our process isn’t so hard to navigate, where wheels are spinning continuously and people are getting nowhere. It’s something that—we’re dedicated to be trying to making a difference here. We thank you for your recommendations. We’ve heard them, and we will definitely put them into consideration, so thank you so much for your time.

The Chair (Mrs. Laura Albanese): And now Ms. Hunter.

Ms. Mitzie Hunter: Thank you for putting the presentation together and for sharing this story. I was curious, when you talked about the information loop. I thought maybe you could talk a little bit more about what you would like to see happen in a proper information loop. It seems what we've been hearing is that while children are in school, all the way up until age 21, there seems to be a very natural communication through the schools, but once that ends, then there's just the absence of consistent communications and an information loop. I thought maybe you could share what you would be looking for in proper communications.

Mrs. Cora Nolan: I guess it's because we're doing the individualized approach, so we're not involved with agencies and that, so we don't get the normal flow of information that you might get through them. We basically depend on family groups to get information about what's going on. I would suggest to most families that they do join local family groups or provincial family groups or access some on the Internet, even, to get information about what's going on around the province. It was just by chance that we got it with this one. So you're doing your own thing, but yet you're not getting the information.

Ms. Mitzie Hunter: But we could utilize the family networks as an appropriate channel to communicate out information about changes and things as they progress.

Mrs. Cora Nolan: Yes, and the Spotlight comes from the ministry. Spotlight: It's the newsletter that comes out from the minister. We get it all the time too. It might be helpful to have something like that in there of upcoming things that are going on at the ministry level, maybe.

Ms. Mitzie Hunter: Sounds good. Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you once again for being here and listening to us today and following the proceedings. Thank you.

HUB FOR BEYOND 21 FOUNDATION

The Chair (Mrs. Laura Albanese): Our next presenter is the Hub for Beyond 21 Foundation. We have the program manager with us. Good afternoon.

Ms. Jane McLaren: Good afternoon. My name is Jane McLaren. I am the program manager for the Hub for Beyond 21 Foundation. We're based out of Cornwall, Ontario, serving Stormont, Dundas and Glengarry counties. We are a day program. We're a non-profit registered charity that is a day program offering services for developmentally disabled persons 21 years of age and older.

As I've been sitting here for the past little while, I've been hearing everyone say that at the age of 21, all the services seem to fall off the map, and we are one of those agencies that are trying to fill the gap. In fact, back in 2010, it was a group of parents who met with the Upper Canada District School Board and identified a real need and a real gap within our area. They got together and, along with the Upper Canada Leger Centre, they hosted a town hall meeting. They really hoped that they would

have 20 or 25 families that would attend that meeting, and instead they had over 100 families come out. It really highlighted that there was a huge need in our area—there is a need, period, but definitely a huge need in our area.

We were fortunate that UCDSB got behind us and supported us, and in January 2012 we opened our doors. We're all of two years old. We're a very young organization. We are 100% fundraising funded. We receive no ministry funds, so we're out there begging and borrowing and writing grants like so many organizations are today. We started two years ago with a very, very small group. We had two staff and just a few participants, and we've grown now such that we have 19 participants in our program.

Our mission is very simple: to offer a structured, meaningful, inclusive and community-based environment where dependent adults with developmental disabilities continue to thrive and grow socially, physically, emotionally and intellectually. We're open to anyone over the age of 21 with a developmental disability. We don't actually have a cap. It's not 21 to 30 or 21 to 42; we don't cap it. We've had 65-year-olds come and apply to be in our program, which really shows the tremendous need. We do have an intake assessment process where we look and see if the needs of the person who is applying match what we are able to offer. That's how we meet and screen out whether or not that 65-year-old's needs are going to be met by our program, or whether they are better served in another program.

The participants come from 9 in the morning until 3 in the afternoon, Monday through Friday. Because we're in a school—we actually are given free space by Upper Canada District School Board—we are closed over the Christmas break, and we have to close for the month of July because they have to come in and do the cleaning in the school. But we are open from August straight through.

We have five different programming areas that we run.

We have recreation, or physical healthy lifestyle.

We have kitchen: The participants prepare their lunch, and they have to clean it up as well. We do have a dishwasher, which is a nice bonus, but they do all of the preparation and all of the cleanup of meals. They also do the menu planning. They do the grocery shopping. They are responsible to go out and pay the bills, to plan it. And you know what? Even with my staff, doing groceries for 12 to 15 people is not really all that natural. I grew up in a little bit of a large family and it doesn't faze me, but it's a real challenge to teach people how to buy groceries and cook and prepare meals for groups that are 12 to 15. So we also have to break it down, because realistically, if our participants go on to a lifestyle of living independently, they are not going to be cooking lunch for 12 people in their home. So we also have to break it down so that they are preparing just for themselves or for one or two people as well.

We do social skills, life skills, and we also do creative expression.

So those are our five areas. They're programmed over four different spaces each day. Everybody does the rec-

reation each day. Everybody, of course, does lunchtime. And then we have two different 1.5-hour blocks where we offer two different programs going consistently.

One of the greatest challenges we face is that we have participants who are coming in and are going to be working towards independent life and towards living in an apartment and gaining independence in the community. Then we have others where that simply is not within the scope of their future. They are working at gaining skills, gaining community, and working towards what they can. But many—well, not many, but we have a few who are non-verbal. So when you try and mesh those who are going to succeed at living independently and we're working with them on budgeting and we're working with them on city transit and we're working with them on life skills, and then you have those who are totally non-verbal and are never going to get there, it's hard to mesh those two together. So we run two programs at the same time, split them off into two groups, so that we can work on needs.

1540

Every single participant has an individualized plan, and we review those plans every single month as a team to make sure we're not fitting and sitting in gaps. We plan weekly. If you go on our website, you will not find a monthly calendar. Our weekly calendar is very deliberate because it allows us to change week by week by week and sit down and say, "Where are we meeting the goals of our participants? Where are we missing them? Where do we need to change on a weekly basis?" rather than getting into a month and getting to the end of a month and realizing, "We really focused on this, but we've left those behind." It allows us an increased flexibility and an increased accountability.

We do have a fee for our program. Our participants are charged \$25 for the day. That includes all of the food and transportation within our program, if they have to get to and from, but any transportation or outings, any special events; everything is covered under that \$25. Most of our participants do claim that back under Passport funding to the extent that they have it.

We've had a lot of successes for two years. We've got Trillium funding; we've had funding from the city of Cornwall. We had a private foundation give us a grant and purchase us a van, which was a wonderful assistance. That allowed us to bring in more participants because we're limited by who we can transport.

If you look under sociology in a hierarchy of needs for every individual, you'll see that there are five: physiological needs like food and shelter; safety, security; love and belonging; esteem; and self-actualization. I think there's a lot of focus within the world of provision on the physiological needs and safety, but then there starts to be a lack. That sense of love and belonging, esteem and self-actualization that allows us to truly grow and function in a community is often what's missed. I really think that comes out of a sense of community.

If you look at our name, we're called the Hub for Beyond 21 Foundation. That's very deliberate. We are a

hub because the heart of our focus is to have a place that develops and encourages a continuing and ongoing sense of community for the developmentally disabled. At the age of 21, they graduate out of school, and school is a community. It's the place, as you heard earlier, where communication is happening, where friendships are happening. Even if you are in a segregated class within, you are still in a community within the school community. There are all these extracurriculars that are going on, and then school is done and you go home. And what do you do? We hear over and over again from our parents that the reality after the age of 21 is television and video games. All of a sudden, they're no longer connected with the friends that they had in school. Our community, when we leave, usually comes from the friends we develop within our employment setting, the friends that we carry through from our friends, our family. We have our family and our extended family; for some, it's our faith community, which, again, often comes through family. But our greatest connections are coming from employment and volunteer opportunities, and that's not existing for many of those who are within the realm of developmental disabilities.

Even when parents are successful in programming, many of those programmings—and I have one parent; God bless her. Her child went Monday through Friday, from 9 in the morning till 5 in the afternoon. That mother ran herself ragged for an entire year and had her child in program upon program upon program his first year after he graduated. She got to the end of the year and she said, "He had a phenomenal year of his time being spent, but it was just putting in time." So the second year, she picked those key programs that he really enjoyed and kept him in those and they both had a life, instead of just programming.

The problem is, I call them "go, do, leave." They go to the program, they do the program, they leave the program. They may develop a friend, if they're going to bowling on Thursday afternoons, and they really may like to go and sit down with Johnny at that program, but there's no relationship or extension of community outside of that program. So one of the key focuses of the Hub for Beyond 21 is the opportunity for the developmentally disabled to create and develop a sense of community and, out of that sense of community, to develop that sense of safety, to develop that sense of self-actualization, that sense of self-esteem, that sense of value that carries them forward as humans and allows them to continue not just their skills but to develop their sense of community and contribution to community and to develop into their future.

Over and over I hear exactly what I've been sitting here hearing this afternoon. We hear from our parents, "We don't know what's going to happen to our children when we're no longer able to care for them." We hear, "I don't know how to access funding. I don't know how to access programs. I don't know how to find programs—or, if I can find programs, I don't know how to validate the quality of the service provider."

SD&G is not a huge city. We have a huge rural community. We have many parents who are taking their now-adult children all over the place in order to find services. They're taking them out to farms in order to do equine therapy, animal therapy and farm therapy, with no way of validating whether the person is a good-hearted person who is working with the developmentally disabled, whether they are a person who has put in the time and effort to get qualified, or whether they are a person who just saw a way to make some money and is going off and doing this. It's the same thing within music programs, the same thing within arts programs.

At the same time, there is tremendous value in connecting and networking out into the community, but it is all falling back on the parents in order to find and set up and program. Then it comes back to this whole sense of community.

After the age of 21, these developmentally disabled adults—they're now back in the home—need adult peers. They need friends. They need adult opportunities in employment, housing, recreation and leisure. They need independence, defined to whatever their specific capabilities and capacities are. They need funds to be able to transition to adulthood in the future. In summary, they need the same opportunities that everyone else had, the same opportunities that we all had: the chance to grow, to succeed and to fail, and to define their future as they walk into it, and not to have their future defined for them by a lack of services or funding.

In the short two years that we have been a program, focusing not just on life skills and social skills but focusing on this whole sense of community, what we are seeing is, we have two that have come to us, worked with us and left our program, and who are now working—living independently and working—which is so exciting.

Out of the 19 we currently have in our program, six of them are actively volunteering. They are with us part-time, and they are out volunteering in the community part-time.

We're seeing an improvement in impulse control and a decrease in negative behaviours in our participants. We're seeing improved social skills, even basic things like the ability to pass food around a table instead of just grabbing it or just sitting there, not knowing that you can actually ask for seconds—basic skills.

Increased communication: Participants who have come in to us with very limited or almost straight echolalic expressions are increasing their communication and their ability to carry on communication.

Increase in peer relations: We are starting to see friendships form within our program now. They leave on the weekends, and they go shopping together. Even more exciting, they're networking into the other programs that are existing, into our community. They're saying, "Okay, the Handi Social Club has a Halloween party, but I don't really want to go alone because I don't know them all that well," so two or three of our participants get together and go. They're starting to network into other groups within our community, but going together. They're starting to connect, network and knit in.

They're learning skills like yoga, Zumba and different things like that within our program, gaining confidence in it, and then they're going home to their neighbourhoods—they're coming out of Long Sault, Ingleside, Morrisburg, Martintown and Alexandria; they may be 45 minutes away from us—and they're joining yoga where they live. So they're becoming knitted into their neighbourhoods and developing friends in their neighbourhoods, because they've gained confidence and skills in the program to take out into the community. That sense of community is so key and is so critical.

Do we have challenges? Absolutely. Fundraising a program is a huge challenge. You're not just sitting there each day trying to figure out how your programming is and how you're going to meet the needs of people. You're constantly sitting there wondering if you're going to have the money to keep this program up and running next week, next month or next year. Fundraising, of course, becomes increasingly challenging year after year after year, because everybody's knocking on everybody's doors, asking for money.

Transportation is an issue. We have people who literally drive close to an hour and a half to get to us, because we are based out of Cornwall. We hope to have satellites so that there is less transportation, but that is a huge challenge, and there is no funding for transportation. Our parents can fund our program under Passport, but they cannot get money back if they have people who drive.

We're 9 to 3. If you work 9 to 5, you can drop your participant off with us and go to work, but what do you do at 3 o'clock? You've got to pay somebody, and you don't get that money back. So that's a huge transportation issue and a huge funding issue.

1550

Hours are an issue. We would love to be able to go 9 to 5 and be able to accommodate so that it makes it easier for parents who are working, but that comes back to funding as well. My staff like to be paid. They aren't paid great gobs of money, but they do like to be paid.

Fund capping: My parents always run out of money in terms of Passport. And where do you put the money and how do you get the money? They're constantly coming to us and asking us, "How does the system work?" They don't understand it. They want us to walk them through it, which is really challenging for us, because then I have to become an expert on all of the system as well so that I can advise them, which I'm not. But they need someone who can walk them through that system because they're confused and they're lost and they're scared that they're not going to get the money and they're going to be financially strapped and stressed.

Space is a challenge for us. We're in one room, and we're very fortunate because the school does give us that room and it's a wonderful room. It used to be a staff room, so we have a kitchen; we have private bathrooms. We actually have a private entrance so that we don't have to go through the entire school to access it. It's in one of the schools that was closed. They just let us paint a wall,

which schools don't do. We're really lucky, but if we had a whole house, the difference that we could make in terms of teaching—it goes back to that full funding issue again.

The other thing is just the time to promote us. We have to go out in the community and make us known. The DSOs don't make the parents know about us. The agencies that should be letting parents know we are there—they don't tell the parents about us. It is up to us to go out and promote in the community and let the parents and the families know who we are, what we stand for and what we represent. That becomes another onus for us and it also becomes more dollars, because we've got to put the dollars out in promotions and fundraising in order to do it. That's a huge challenge.

We are very fortunate that we're a United Way agency. We were the only new United Way agency accepted in our area. Again, that comes with going out with United Way and doing the sponsorship, but it also really assists us in promoting and getting known.

Beyond 21 has no intentions of stopping. We have no intentions of giving up. As you heard earlier from Karin, one of our plans is to develop and expand into residential and to have a residential setting for adults. One of our other dreams is to have a respite care centre for adults as well. We have the three facets. We also hope to expand into social enterprise so that the developmentally disabled will have increased employment options. In the future, that's where we hope to go. We're just starting, but we definitely want to go and expand.

There are a lot of needs for this population. The day program is not the be-all and the end-all for every single one of them. We want to expand; we want to be there; we want to just do everything we can.

If I had to encapsulate us in a nutshell, I'd say Beyond 21 is about dreams and visions. It's about the value of community, it's about the value of belonging, and it really is about seeing potential instead of seeing disability.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you for a very insightful presentation into the programs that you have at the Hub for Beyond 21. We have one minute each, so that we don't get caught behind.

Ms. Sylvia Jones: Does that mean I just talk faster?

Okay, so I'll ask the silly question. I'm assuming you have put together a funding proposal in to MCSS.

Ms. Jane McLaren: No.

Ms. Sylvia Jones: Why not?

Ms. Jane McLaren: When the board first formed and approached MCSS, they were told that they would not be funded. Even the residential: We have looked into it and we've been told, "There is no funding; do not apply."

Ms. Sylvia Jones: You have to put the words "pilot project" in front of it and then you at least get in the door. Okay. Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: I just want to say thank you, because it's such an encouraging, exciting story. If any-

thing deserves to be funded, it sounds like yours does. Again, we see this wonderful initiative coming forth, starting with parents and catching steam and going on. Clearly your passion for what you do is catching, and I think we've caught a little bit of it.

I just want to thank you so much for making the trek down here. You have so much else on your plate to do, but thank you for letting us know what it is that you do, that you love, because you clearly love it.

Ms. Jane McLaren: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzi Hunter: Thank you for presenting an innovative program approach. I was going to ask you how you plan to scale up. I think you have some ideas there. Maybe the work that MaRS is doing—you can link into that, because they are looking at scalable solutions across multiple communities.

I think it's good that you're a United Way agency. It adds a lot of credibility to other funders, so I think another cycle of that is very appropriate.

I do agree that the pilot approach is a good path to linking in to the government, but with an agency partner. I think that having that conversation—there is an openness for that. So I would really encourage you, either through your Community Living or advice through the DSO—of an appropriate agency partner to talk about your residential programs, to talk about your scalability. I would believe that they would be open to that.

I believe my colleague here also has a question.

Mr. John Fraser: Just very quickly, I wanted to say thank you very much for your presentation. Your comments on community and belonging and what people need really connected very well with an earlier presentation by the MAPS people about people having relationships outside of caregivers post-21. You're filling a gap that's there, and that's very important. It's a good thing that you're doing that. Thank you very much.

Ms. Jane McLaren: Thank you.

The Chair (Mrs. Laura Albanese): Thank you again.

MS. ANDREA STADHARD

The Chair (Mrs. Laura Albanese): We'll now move to our next presenter, Andrea Stadhard.

Applause.

The Chair (Mrs. Laura Albanese): You have fans in the audience. Good afternoon.

Ms. Andrea Stadhard: Good afternoon, everyone. Sorry, I'm very nervous. This is my first time ever being at a forum like this, so bear with me.

The Chair (Mrs. Laura Albanese): Do not be nervous. If you need any water or anything, just feel comfortable and make your presentation.

Ms. Andrea Stadhard: I'll probably get water after.

I'm a front-line worker—can I say where I work? I work for Tamir foundation. It's a Jewish organization that supports adults with developmental disabilities and other dual diagnoses. I kind of just want to go through the way the budget is set up now and how the participants

are living right now, based on the current budget, so just some scenarios. We can go through my handout a little bit afterwards, if there's time.

My first scenario is a man in his mid-20s. He has autism spectrum disorder, a seizure disorder, and he is also non-verbal. In the past year, he has had an increase in violent behaviour towards his peers, staff and his environment. It was recommended by his psychologist and his behaviour management consultant that he take a vacation from his day program to allow him to regroup. His parents also agreed with this recommendation. Almost immediately after the recommendation was tabled, it was denied by his residential supervisor, stating that there was no additional money in the budget to support this individual. This person continues to attend his day program and continues to have violent outbursts—an otherwise gentle man who enjoys giving hugs to preferred friends and staff now needs a break from the everyday. When he becomes violent at program, he takes away from the other participants. When he becomes violent towards his peers, he instills fear and distrust. When he becomes violent towards his environment, he damages items the other participants depend on for day-to-day supports.

Just recently, this person experience an unexplained increase in seizure activity and required a visit to the emergency room. The staff supporting him had been working a 12-hour shift already and went to the hospital with him. She ended up having to extend her shift, so she was there for 15 hours. When she called the on-call supervisor to see if she could be relieved, the supervisor said that there was no one else to cover and maybe she should call the parents. So she ended up calling the parents. The parents said, "No, it's not convenient for us to stay at the hospital." She called the supervisor back and the supervisor said, "Okay, just leave him alone at the hospital." Just as a reminder, he is autistic, he is non-verbal and he acts out physically. Even people whose first language is not English have a translator to ensure the best possible health care.

My second scenario is of a young man with a developmental disability, also non-verbal, and by all accounts very healthy. He has been experiencing back problems, rendering him unable to walk. He would benefit from regular massage therapy as a preventive measure but cannot afford the service as he must save his modest money for his personal necessities. Providing this individual with additional financial support now may prevent him from depending on the use of a wheelchair later.

1600

My third scenario: An older man with Down syndrome has been working for many years at the same job, shredding confidential documents for the government. He is reliable, trustworthy and he works hard. He lived in an apartment in a supported independent living setting and took the bus to work independently. He began to show signs of dementia, and when it became unsafe for him to continue living in his SIL apartment, he moved into a group home that provides 24-hour support. He tried to get access to riding on Para Transpo, but he did not fit

their criteria, so he continued to take the bus to work. One day on his way to work, he made a wrong turn and was spotted walking on the Queensway.

My last scenario: Here's a story of a senior male with a developmental disability living in a group home. Although he can speak, he is considered non-verbal. In his earlier years, when he lived at Rideau Regional Centre, he had the potential to become aggressive towards others, but it could be prevented once staff were aware of the antecedent and could change things around to avoid physical aggressions. Now he is much older. He has less tolerance of situations and becomes violent towards others without explanation. He aggresses against others, including members of the community. This person has been exempt from programs and now remains at home with one-on-one staffing. The only difference between this scenario and the one I shared earlier is that, in this instance, the aggressor has been violent against a member of the community. He gets to stay home because it costs less than a potential lawsuit.

Those are my scenarios. All of these things have happened in the last year and a half, and there's a lot more that go with it.

With my handout, I have bullets of just how the budget is affecting the participants now. Just to skim over a couple of the bullets that are really, really important—probably our fifth bullet down: Persons with developmental disabilities currently live on an extremely modest monthly budget of an average of \$113 a month. That money is supposed to cover personal hygiene, entertainment, extracurricular activities and everything else that can come up under the moon.

An example of how this whole system isn't working right now: Imagine getting free tickets to your favourite sporting event but learning that you can only watch half the game because the staff supporting you at the game finishes his shift before the game's end and his employer is not willing to extend the shift. Would you only go to half of a game? Not many people would.

Vacation: Vacation is defined as a period of time spent away from home, school or work in order to relax or travel. People with developmental disabilities have a very modest income after they pay for their shelter and their food, so a vacation for a person with a developmental disability is maybe three days and two nights. That vacation also includes going on vacation with the people that they live with and the people that they go to day programs with. So they're essentially not getting a break from any of their everyday life situations. They're always with the same people. We're not really doing it justice when we could be expanding it to saving up to go to a different city with friends from another group home or friends that you went to school with. We're not really keeping that inclusion part of it alive because it just doesn't fit the budget.

There are residents in need of updates to accommodate declining changes in individuals' physical, emotional and mental states. For an example, we have a group home with eight individuals. These guys have been together for

years and years. They love each other. But now there are forms of dementia that are coming into play, so where you had two individuals who were the best of friends, one is now targeting the other. So one is essentially being bullied by the other person. There's no help. Where it used to be fine to have one staff to stay asleep in that house, it's not possible anymore. Because the dementia is taking over this person's life, he's becoming unsafe to himself and to others. He's throwing things down the stairs. He's sneaking into other people's rooms and trying to aggress against them in the middle of the night. So now his housemates don't feel safe. There has got to be a system in place where we can support the people with changing needs as well as still giving the positivity and the respect and the dignity that we're supposed to be giving to the people who are watching all of this go on around them.

Am I out of time?

The Chair (Mrs. Laura Albanese): You still have time.

Ms. Andrea Stadhard: Okay. For day programming, I am a front-line day-services worker, and what we're seeing now is our day supports are running at full capacity. I've been at the same program for 10 years and I have seen the staff number stay the same, but the numbers increase. When you have such a diverse group of individuals who come in and they want support, we're supposed to be able to provide individualized services. We're supposed to be able to look at supports for someone who has autism, who might need the sensory part of his life fulfilled, before going on to something else. It's not possible; it's just not working. And it's not working because staff are overstretched. I'm not even supposed to be here to talk about staff—it's all about the guys—but you have to understand that when you add 10 more people because of Passport funding to a program where the staff doesn't increase, it doesn't get better.

My last blurb on Passport money: It sounds great when you introduce it and you say, "Here, families. Take this money and find a program that suits your son's or daughter's needs." The problem with that is when you start warehousing people—because this is essentially what it is—and fitting as many people into a day service as possible so that they have day supports to give their family a break, we're overwhelmed. The system is overwhelmed. There's not enough vans; there's not enough staff.

We have all the opportunity; we have all the community supports. We just can't get to them because we're dealing with one-to-one behaviours. We're dealing with people with pica who cannot be left alone because they will ingest something that could potentially kill them. The risk is different because we're pooling people in the same group. You cannot lump everybody underneath the same—it's not fair.

It's great to provide day services. People need day services, and sometimes without the day services they have nothing else. We know of people who are staying home with their parents because they don't even know

what supports are out there, or they do know what supports are out there and the government has given them this Passport money, but there's no space for their children.

I talked to a woman last night who was with her son at Thursday Nights Rock. She has a good family support system, but it shouldn't be his family who's taking care. He needs that social involvement, which he is missing.

One more example: Loeb dances. An agency, OCAPDD, has Loeb dances for every holiday. They're awesome. All the guys like it. I went to the Christmas party last month and I saw a participant dancing on the floor with her mother. When you think about it, it's not inappropriate to dance with your mother, but if you're at a social event with your peers, you should be dancing with your friends. There is something amiss when these guys don't have friends, and I feel bad when I say to them that I'm not their friend because I'm paid to be there. It's not a fair statement, but it is the reality, and we have to be everything to them. So please keep that in consideration. Open up the wallets and support these guys the best way that you guys can.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your honest presentation.

I will turn it over for questioning, and we'll start with the NDP. Miss Taylor.

Miss Monique Taylor: Great, thank you.

Thank you for your presentation and thank you for being here today and for knowing that there's a need. I mean, it's quite obvious, through the people you spoke of, through the things that you say are necessary for change, that you get it. You're working in the system, you're seeing what's happening on a day-to-day basis, and you know there's a problem, and you've taken the time to step up to that problem and say, "I need to do something about this."

1610

By doing that, you're here and you're speaking to us today, because we've also realized that there's a need. That's why we've called people together to please give us a suggestion. You're living it every single day with people in these programs, and families are feeling these struggles every day. It's so important that we're hearing these struggles, and that we work together to try to find solutions.

You were talking about friends, and I'll put a plug in: In my city, there's a program called Club GAIN. It's for young persons—I believe 13 to 24 are the ages that can attend—and no parents are allowed. You're not allowed to bring your worker. There's adult supervision there, and it's about being with your peers. They dance, and they're allowed to touch in a respectful way, and they're allowed to kiss. It's helping with that sociability. They're building relationships, they're being with their friends and they're finding love in this world. There's no government funding for that one either, but it's something that people are taking initiative on, standing up for the needs that we see in our communities, so that's what I have to say on that. Thank you for everything that you do.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Ms. Stadhard. I really appreciate your frank approach in which you shared those stories and what you see every day as a front-line worker. I see a lot of compassion and joy in you, because you're talking about some very tough things, but you're still able to present them in that way. I really appreciate the work that you and your colleagues and peers are doing.

I have two separate questions, just from your comments. The day supports, combined with the natural supports to the families—from your perspective, how do you see that working? Because what you're saying is that the system is stressed and overwhelmed, even within the day programs, just due to the pressure for space. Families are relying on the day programs so that they can get a bit of a break or continue to work, but they very much want to continue to be involved in their son's or daughter's life to provide some of those natural supports. When does that work well? That's my question.

Ms. Andrea Stadhard: The thing with that is that their parents, before the Passport funding—so for the people with disabilities who already had a spot in their day services, for their parents, it was an expectation: "This is where I would send my child, this is the programming that will get done, and I'll be happy with it." There was an expectation, like sending your kids to school. You just knew every day that your kid was going to school, there was a place for them and they would be safe.

For the people who are coming in with Passport money—it really is the Passport money; there really is nothing else—they're coming in and dictating what they would like to see. That's fabulous, but give us the structure, because it would be very honourable to be able to give that individual every single thing that they need to meet every goal on their list and check it off. We can't do that now, based on the numbers.

We're very grateful when parents take some time off and come in to volunteer. They come and see what we're doing. They see what we're working with. We don't even have a functioning TV, so it's up to staff teaching a class on the wilderness to bring in their tablets, pull up a video—because we actually have WiFi—and say, "This is what it is."

To be able to go to a museum, that costs money. The frog exhibit was at the Canadian Museum of Nature the other day. It was too much money. We couldn't afford to go, so, "Let's go back to program, and look it up." There are just so many things amiss, because it's a fish pool. It's a barrel of fish, and now we're thinking that all of these fish are the same. It's not right.

Ms. Mitzie Hunter: How many people are in your program?

Ms. Andrea Stadhard: In my location—I'm on Donald Street—we have 30 people, and we have two different programs that run out of there. The program that we work in is a life skills and job skills program. Our sister program next door is more recreational. So,

depending on your level of need is where you're going to be.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Hunter. Ms. Elliott?

Ms. Christine Elliott: Thank you very much, Ms. Stadhard, for coming forward to us today. I think you've brought a unique perspective as someone who is working on the front line in the day program. You've brought a number of concerns to us that, frankly, I wasn't aware of before, so thank you for that.

You've talked about the division of your day programs into one that's based more on life skills and job-readiness skills, and one based more on recreation.

You also mentioned some of the concerns about some of your aging participants, some of them with more aggressive behaviours and perhaps early-onset Alzheimer's. Is that another program that you would see would be useful to open, separate from the other two?

Ms. Andrea Stadhard: Absolutely. I think that it would be beneficial to have a program that deals specifically with people who are going through dementia-type issues as they're getting older. They're getting older, and you can't send them to a seniors' home. What has happened in the past is that you sent somebody with a developmental disability, with dementia, to a seniors' home. They're not trained to work with these individuals.

We go to school to work with these individuals. We want to see the best for them. If they snap, you can't send them to the ROH and say, "Please fix this." It's not a fixable thing. There's got to be another outlet that supports our guys properly.

Mrs. Christine Elliott: Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you again for presenting to us today.

PARTNERS FOR MENTAL HEALTH

The Chair (Mrs. Laura Albanese): We'll now ask Partners for Mental Health to come forward. Good afternoon, and welcome to our committee. As you have heard, you will have up to 20 minutes for your presentation. If it's any shorter, we'll have time for comments and questions. You may begin any time.

Mr. Jeff Moat: Thank you very much. Maybe we'll start with some introductions.

The Chair (Mrs. Laura Albanese): Yes, please.

Mr. Jeff Moat: My name is Jeff Moat. I'm the president of Partners for Mental Health.

Mr. Michael Dixon: I'm Michael Dixon.

Ms. Janet Osborne: My name is Janet Osborne.

Mr. Jeff Moat: What we'd like to do this afternoon is take you through an initiative that our organization has pulled together in response to a pressing issue that's facing our young people today.

Before I get into the details of that initiative, I would like to start by having Janet Osborne share her story. Over to you, Janet.

Ms. Janet Osborne: I'm one of the volunteers for our local Partners for Mental Health. The reason I was looking for a group to join is because it will be three years in February when we lost our 18-year-old son to suicide. My first reaction was, I can't not do anything. I have to prevent any other young people from taking their lives.

What I'm really hoping to achieve by all this is, the school system—even though he was 18, he was still in the public school system. The teachers were seeing different affects from him: not going to class, not showing up for exams, not handing in homework. After we met with the school afterwards, we were told that. Most of all of this, we didn't even know, because he was 18.

We understood from the principal that he was brought in to some of the teachers and was given a pep talk to do whatever he can. But other than that, because he missed so much time, they basically wrote him off as a dropout and never really addressed the situation.

The day before he took his life, he actually told one of his close friends that he was planning to kill himself. In her view, she figured that she did the right thing by just trying to talk him out of it. She didn't tell us; she didn't tell her parents—other than what she knew: "Well, I'll sit and talk to you and tell you that, no, you don't need to do that, and we're here for you," and whatnot. But he went ahead and did it anyway.

1620

My biggest issue is, our children are being taught at school about drug issues; they're taught about sex education; they're taught about puberty and all those things, but never have they ever spoken about mental health. They're not taught what to do when their friends are talking about suicide. They're not taught to go to a parent; they're not taught to go to a guidance counsellor. They're watching their friends deteriorate into drugs and alcohol. They're seeing the changes.

I'm dealing with one of his friends right now who has come forward just before Christmas and almost broke my heart saying he can't live with the guilt anymore that he couldn't have stopped him. Now his parents have to pay for psychology treatment because I recommended that he go see a psychologist before he does harm to himself, because his attitudes were pretty much the same as my son: He never spoke to anybody. I'm just fortunate enough that he came forward and said, "I can't deal with this anymore. Can you please talk to me?"

We need to have the funding and the resources in Ontario spread across all these aspects. It's not a fix in one area; it has to be across the board. Students need to know and it needs to be part of the curriculum, I would even suggest, right from middle school on, because they're getting younger and younger all the time.

I strongly urge you to listen to what Jeff is proposing. Hopefully it will trigger some hearts to help out so we don't lose any more young people, because there are too many being lost already.

Mr. Jeff Moat: Thanks, Janet. Sadly, the story that Janet tells is actually more common than we may all

think it is. Too often we feel that suicide, the death of a young person taking their own life, is someone else's problem, but we know that for every death by suicide there are hundreds of attempts, and that for every attempt there are hundreds of ideations. When you actually do the math, this touches hundreds of thousands of young people. The reality is, it is in all of our kitchens; it's in all our backyards. This is an issue that touches all of us.

Before I get into some of the specifics of what we want to put in front of you, I just wanted to take a brief moment to tell you a little bit about the organization called Partners to Mental Health.

We're a national charitable organization. We're accredited by Imagine Canada. We were founded by the Honourable Michael Kirby, who, by the way, sends his regards to everyone in the room today. He created this organization to improve mental health in Canada by mobilizing Canadians to accelerate, in his words, a social movement which collectively will serve to break through the social prejudice that surrounds mental illness and effect real and lasting change.

Through active and collaborative engagement of individuals, schools, businesses, community leaders, governments and other stakeholders, Partners for Mental Health is beginning to open a dialogue, educating and informing Canadians, changing attitudes and behaviours, influencing policy, raising some money and beginning to redefine the current norms around mental health and mental illness, because what we call normal today is actually quite abnormal.

For a young person, regardless of where they live in this country, to wait, on average, 12 months to access mental health services, in my opinion, is actually quite unacceptable. If that's the norm, that's abnormal.

Three out of four young people who need services in the mental health system don't get them. Imagine if we denied three out of four kids cancer therapy or that wasn't available. What do you think would happen? It would be completely unacceptable, yet because it's a mental illness we accept the norm. Only one out of four kids that need access to these services get them.

Suicide is the number one cause of non-accidental death for young Canadians. We lose an average of 760 kids a year. That's the size of a typical high school in this country. Almost all young people who die by suicide have an underlying mental health problem. So we took it upon ourselves as an organization to create a campaign called Right By You to rally Canadians from coast to coast to coast to lend their voice and to take action in support of suicide prevention, and ultimately to ensure that mental health-related services, treatments and supports are available to all young children when they need it, because right now, if a young person needs it, they're going to wait, unless you have the financial resources to do it. We have a classic two-tier system in this country: We have the haves and we have the have-nots. I think for most Canadians that would be unacceptable.

We're calling on provincial and territorial governments to double the number of kids receiving access to

mental health services and treatments. Right now, 500,000 young people get those treatments. Over three years, we'd like to double that number. When we look at programs in Australia, in working with some of our subject matter experts here in Canada, we've come up with a model that we think is certainly something that is worthy of further investigation. It's modelled off an EAP system, an employee assistance program. In Australia, what they do is they provide a certain number of sessions, and these sessions are provided by not just psychiatrists, but psychologists and social workers and other accredited psychotherapists.

That's what we're proposing. We're looking at providing kids access to eight sessions provided by one of these professionals, and if we look at an average hourly rate of about \$125, that's \$1,000 per child. Are we not willing to invest \$1,000 per child? Across all provinces and territories, if we want to double the number of kids getting those treatments, that works out to be \$500 million over a three-year period for all the provinces and territories. It's not the be-all and end-all, but it's a start. It gets kids into the system, and after eight sessions, if they need triage deeper into the system, then that's what will happen. But let's get kids access to the treatments they need sooner rather than later, because you know as well as I do, if a young person—or any person for that matter—is denied treatment, and they wait, what do you think happens over 12 months? Their condition deteriorates, and sadly results in tragic consequences, like suicide.

I'll pause there, and thank you for your time.

The Chair (Mrs. Laura Albanese): Thank you. It's a touching presentation, to say the least. I believe it's the government's turn to start this round. Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much. There's a lot here to unpack, and I know we don't have a lot of time. I was wondering, in terms of the numbers that you're capturing, does that include aboriginal youth as well?

Mr. Jeff Moat: That's a great question. Certainly, when we talk about service provision, we talk primarily in urban environments. But what's really important is the fact that when we talk about problems in urban communities, I can guarantee you that the problem is exacerbated in rural communities and deplorable in First Nations and Inuit communities. What we've put forth in our more detailed propositions is the fact that we recognize the cultural differences in these communities and that the treatment, whether the delivery channel or the type of treatment, needs to respect the cultural differences.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation, and Ms. Osborne, I'm very sorry to hear about your loss. I just want to acknowledge that piece.

During the past year, all three ministries—health, education, children and youth services—made significant announcements in Ontario. Are you aware of these announcements?

Mr. Jeff Moat: Yes.

Ms. Soo Wong: And have you had any conversation with any of the ministries, particularly in the pieces that

deal with nurses in our schools targeting for mental health, and the recent announcement from Minister Duguid for training, colleges and universities to support post-secondary students? So I just want to hear a little bit about your conversations with the different ministries about your program.

Mr. Jeff Moat: The conversations we've had, and thankfully, by having a chairman like Mr. Kirby promoting this particular policy—he has been successful at socializing this particular policy with every deputy minister, in most cases almost all ministers of health right across the country. I'm happy to say that the receptivity to this has been quite favourable.

1630

Certainly, there have been some changes, as you have just recently spoken about. The reality is that mental health services in Ontario and across the country have been historically underfunded, which has led to the patchwork of services that we have now. No real mental health care system truly exists. We just feel that it needs to be given a larger share of the health care budget.

In looking at CAMH's figures, they show that mental illness—I'm looking at my numbers here—constitutes more than 15% of the burden of disease in Canada, yet these illnesses receive, still, less than 6% of health care budget dollars, and 60% of family physicians rank access to psychiatrists in Ontario as fair to poor. That is still unfortunately the situation we contend with. Certainly, some positive strides have been made forward, but I guess we're saying that more needs to be done.

The Chair (Mrs. Laura Albanese): Mr. MacLaren?

Mr. Jack MacLaren: Thank you. Jeff, I'd like to thank you for coming. You speak well and you identify a problem we're all aware of and you just highlight it in a very intense way.

Janet, your words are very powerful. Sorry for the loss of your son.

Michael, you and I know each other. You've come to my office and talked about Partners for Mental Health and your Right By You program. I think we were in the Hazeldean Mall one day when you had a booth set up to promote it, so I'm very aware of what you're doing. Who you are and what you're doing, I'm aware of because of you, Michael, so thanks for that.

We all read about these terrible tragedies that happen. I have three kids who went through high school, in West Carleton high school, which is rural, and that was about 10 to 15 years ago, depending on which one of my daughters you speak of. In a couple of years, it was three kids who took their lives. It was a shocking time in the school. It was just devastating for families and the community, and nobody could quite understand it. It's powerful. So thank you for coming here.

We know we need to do better, and we hear you, and I guess we're the right people to talk to because this committee is dealing with the developmentally disabled and mental health. So thanks very much, Michael, and I look forward to talking more with you. You're a great advocate in our community here, so thank you for all you do.

Mr. Michael Dixon: Thank you. One thing: As a funeral director for over 20 years, I've seen this firsthand. I've seen the numbers go up and up and up and the ages go lower and lower and lower.

One thing that I've always remembered and has really got to me is that we talk all the time. We tell our kids that, "When there's a problem, please come and see us as mom and dad." We had a young man who passed away. His family came to our funeral home, and it was in between Christmas and New Year's. He was a popular kid. He played hockey; he was in the music club; he was in theatre; he played baseball—lots of friends. We tell our kids to do the right thing. He did the right thing one day, and he went to his mom and dad and he said, "You know what? I'm just struggling. I'm doing well in school but I'm not happy."

So mom and dad do the right thing by going to their family doctor. They had a meeting with the family doctor and that family doctor did the right thing too and he went and got him an appointment with a professional. But the problem was, that appointment was seven months down the road, with no help in between then and seven months down the road.

Unfortunately, this young man, who probably could have brought a lot to our country, didn't see any way out. I've always remembered that, and I think it speaks to what we're talking about too.

The Chair (Mrs. Laura Albanese): Ms. Elliott?

Mrs. Christine Elliott: I know we only have time for a short comment, but I'd just like to thank all of you for being here. Janet, despite your terrible loss, thank you for having the courage to come forward and be so involved with such a worthy organization. I think you know I am very familiar—I have met with your founder about it. You know that I'm a big fan. I think it's really important because we've talked about a lack of services for people with developmental disabilities—that's what we've been primarily talking about here, but we know that about 40% of people are also dually diagnosed. We know there's a high incidence of mental health troubles with people with developmental disabilities as well.

We need to build capacity. One way of doing it is through the way that you have promoted, with a number of services being available at no cost to families. I think that's something that we should take a look at implementing into Ontario's plan because, as much as we've implemented policies and procedures for early diagnosis, we also need to be able to follow that through with treatment.

Thank you very much for being here, and we'll look forward to doing whatever we can to promote your program.

Mr. Jeff Moat: Thank you very much.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Again, just to echo everyone, thank you for your presentation and thank you for your incredible courage in coming forward. Our hearts and our prayers are with you always.

I'm a United Church minister by trade, as well as being a politician, and I've worked with a number of

families over the years who've lost children. I also have seen it first-hand, working with one of my own children trying to get through the system, but with happier results than to end up committing suicide—still alive today and grew up. But it was a struggle, so I'm absolutely in support of what you're doing.

There's another organization of parents in Toronto. I don't know if you've made links with them or they with you. It's called Tragically OHIP. It's a group of parents who got together, came to Queen's Park and did a presentation. I supported them. All of them have had situations with their children, some successful and some not, all with mental health issues. Most of them are parents with some means, so they mortgaged their homes to get the help they needed and sent them out of province, almost invariably to the United States, for help. They were advocating for OHIP coverage for more psychiatrists and more psychologists for children so they didn't have that seven-month wait period that you speak about. I'm just putting that out there as an organization you should make a connection with. They even have mugs and everything. They've got their own huge thing happening in the GTHA.

But anything else we can do to help—and certainly through this committee we will be advocating as well.

The Chair (Mrs. Laura Albanese): And I too want to thank you for bringing this to our attention. Every child and youth deserves support, especially for suicide prevention. To you, Ms. Osborne, I just want to say no mother should have to go through what you went through, and thank you for your courage.

TIPES

CASPA

The Chair (Mrs. Laura Albanese): Now we'll hear from TIPES and CASPA.

Ms. Mitzie Hunter: Madam Chair, while the next presenter is coming, I wanted to just let the committee know that the presenters—not these recent ones from Partners for Mental Health, but the ones before—were from the Tamir foundation. I know that some people were asking. It's the Tamir foundation here in Ottawa.

The Chair (Mrs. Laura Albanese): So is that all clear? Okay.

Good afternoon.

Ms. Deborah Wyatt: Good afternoon.

The Chair (Mrs. Laura Albanese): We're ready for your presentation. Thank you for being here.

Ms. Deborah Wyatt: Thank you for having us.

The Chair (Mrs. Laura Albanese): As you know, you'll have 20 minutes, and if it's shorter than that, then we'll have questions and comments. You may begin.

Ms. Deborah Wyatt: Can you hear me?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Deborah Wyatt: I'm Deborah Wyatt. I'm clinical director and co-founder of TIPES, Thinking in Pictures Educational Services, and this is my twin sister,

Jennifer Wyatt, who is the executive director and co-founder of TIPS.

We also created a not-for-profit called CASPA, which we're going to talk about a little bit later. But first, since most people know us from TIPS, I'm just going to give you a bit of a background about our charitable organization.

TIPS is a charitable organization that caters to children, youth and adults with autism and related or additional exceptionalities. Pretty much our charity was created to support the families in any way we can. We offer multiple programs, respite, IBI therapy, consulting to parents and professionals and social integration. In collaboration with psychologists, we're also able to offer things like ADD-ADHD coaching and psychological assessments.

The mission: Really, we have three goals of why we created TIPS. The number one thing was that we felt that it shouldn't really matter what the diagnosis is. As long as we're able to support these families and these children, we will. Often we do find that some children may be given a diagnosis of autism and another exceptionality, and for that reason they may not be eligible for any support from government funding. A second goal was to have the proper number of professionals in the field, because it is still quite a new field. The third goal was to have charitable status, so we could fundraise monies to offset the costs of IBI therapy—which, I'm sure you're aware, there's a long waiting list, so parents are feeling that they need to get into intervention as early as possible so they can better help their child reach their full individual potential.

1640

With that said, I wanted to talk a little bit about our history over the last 11 years. I am grateful, and so is Jen, to be able to have met those three goals, and we do intend on being able to meet that moving forward.

I would like to paint a picture for you, to better understand what it is like to live with a child on the spectrum or with other diagnoses, to understand what the hardships are that these parents are going through right now. There are two routes, which I'm sure you're all familiar with; if you guys are aware, I can skip that part, but—

Ms. Jennifer Wyatt: The DFO and the DSO.

Ms. Deborah Wyatt: The DFO versus the DSO. Would you like me to go through that? Yes? Okay.

So there's the DSO option: When a parent first starts to see that there might be some issues, they describe to us that they will go to their GP, and they will say, "They are not reaching their milestones." Often, doctors will say, "Well, let's wait a little bit longer to see if we can have some progress," and you'll come back in a couple of months. The parents will then come back, and they will end up referred to a psychologist. To get the DSO option and have the government provide that assessment, it's about a year to get that assessment completed, and then they're able to sit on a waiting list to eventually receive treatment, which seems to be about two or three years to be able to get, here in Ottawa.

Once they reach the government-funded agency, they are offered a DSO position first, and then parents can go to their programming and get the IBI. Once they're finished with the IBI, they will transition into a school program, and that's when parents continue to feel that they're having a bit of a battle, because it seems that there aren't enough resources within the school system to support their children. Once that's completed, they find that, with university and for adult life, there is a lack of services and supports to be able to get them into vocational skills programming and whatnot.

Should the child decide to do a DFO option, the parents are having to pay approximately \$1,500 to \$2,500 for a psychological assessment, but the advantage to that is that they then get on the waiting list a little bit sooner. They can start intervention right away and hire a private provider such as TIPS, and then parents are paying out of pocket to enable their children to reach their full individual potential as soon as possible.

By the time they get the call, two to three years later, they often get the option to go to the DSO or the DFO. If parents want to wait for DFO, it seems that they have to wait between six to 18 months to be able to get a direct-funded option. A lot of parents, we find, feel that they just want to stay with the private provider they're at, because their child has already made great gains. With transition, they just feel that they want to continue where they've started, so parents are then forced to wait a little bit longer to get that funding.

Something that we're finding is that they've done so well in the three years that they've been with us while waiting that sometimes they don't get funding at all, because their child has progressed so much. Meanwhile, we've got parents who have almost lost houses trying to afford what's best for them. Although we do do fundraising, with the number of children we have coming in every year, we're not able to offer it for free. The most we can do is offset the cost.

It goes on from there with the government not having enough resources in schools—and then looking for adult life. Many parents say to us now that they don't know what's going to happen when they're no longer here. Who's going to take care of their child?

That kind of paints the picture of what these parents are going through.

Now I'm going to pass it over to Jen, who's going to actually speak about CASPA. CASPA was created, really, to be more of an advocate program, and to help with collaboration. One of the problems that we were finding is that there aren't enough resources, but I think that we need to start working together as professionals in the field, so CASPA was created to focus more on regulating—and to have everybody come together.

She's going to talk more about that within CASPA. That's the document that she has provided to you. She's going to give further details on things that we feel the government could be doing to better the support for these families.

With that, I guess I'll hand it over to you.

Ms. Jennifer Wyatt: Is it possible to get a time check? Because I want to leave time for questions.

The Chair (Mrs. Laura Albanese): We're at almost seven minutes, 6:50.

Ms. Jennifer Wyatt: All right. So I'm going to skip down to what we already know. IBI is the only documented and highly supported treatment option for individuals with autism to potentially catch up to their peers in their learning trajectories. This is very possible. The most recent studies suggest that the highest likelihood of success in IBI, defined as a change in the rate of development, is achieved by using a high-intensity and relatively long duration approach.

Do you have it?

Ms. Deborah Wyatt: Yes, it's page 1 if anybody is looking.

Ms. Jennifer Wyatt: The majority of large population studies recommend two or more years of intense therapy lasting about 30 to 40 hours per week. IBI is most effective when children are younger. Research has shown that the most critical period to provide services is under the age of three and that to achieve significant results above that age requires an increasingly high cost per case.

Problems: Currently, there are long wait-lists that can last anywhere from 18 months to three years to receive services. The high cost of IBI on families makes therapy hard or impossible to access. There is inconsistency between families in terms of funding across the province. The longer wait times mean that the likelihood of the effectiveness of IBI at a lower intensity is reduced.

Currently, there is no governing college or body, so individuals are practising IBI without proper credentials or experience. So now we have people practising who don't really know what they're doing.

Due to financial and geographical constraints, not all families have the ability to shop around and choose the therapy that the parent determines is the best for the child.

The current system penalizes families for providing their kids with privately funded early intervention. The current system penalizes parents for opting for DFO, as there is a provincial cap of \$39 per hour and rules that often require they pay for additional services.

Schools are reluctant to allow IBI service providers into the school to ensure transition, which reduces the chance of the child successfully integrating, and IBI is not currently covered by all private insurance providers in Canada.

So the results: Low-income families are discriminated against because they cannot afford the IBI while they sit on the wait-list. Families with higher incomes are also discriminated against, because they are penalized during the assessment for IBI they can afford. Parents complain that children are being discharged without transparent, non-discriminatory, ethically sound processes being followed and with little recourse aside from complaint mechanisms that lead to the same individuals. Parents complain that some children are being discharged unfairly in efforts to make the wait-list move. Not all children

are being treated in a similar fashion or according to principles of fairness and best practice.

The effectiveness of the government's IBI program is being reduced because best practices, applying intensity and duration, are not being followed, resulting in more money spent. Long-term savings to the government and taxpayers are not being realized at the levels they should be. Again, IBI is not implemented as intensely as it should be for long enough—i.e., children finally get funding, then, with not enough funding, they don't continue the therapy, and then they regress, and then we end up having to pay for them later on as well.

Okay, so if we skip on through, we've come up with some things that we thought might help with these problems. What needs to be done? I'm on page 3.

Ms. Deborah Wyatt: We like to focus on the positive, the answers and solutions, if we can.

Ms. Jennifer Wyatt: Yes.

Create a governing association, a standard supervised by a governing board, which provides licences for all centres. Now, this is something that we have already done, and I'm actually working with Autism Ontario and Toronto to try and collaborate on this approach and get this completed. The association will also be responsible to cap and revise the hourly rate price each service provider can charge. This should prevent, hopefully, inflationary issues with future funding.

The provincial government can directly pay an approved service provider chosen by the families, as an efficient and effective mechanism for guaranteeing that funds are used appropriately. Government can continue to audit the centres if required. I assume that will probably be something you still have to do.

The association will be responsible to audit the centres to ensure they continue to meet the professional standards, and the association, which we're already doing, will also work with insurance companies to try and push for IBI to be covered by group benefits. We did have a very positive conversation with one of the insurance companies, actually. We asked for \$10,000 a year, and they said that if we don't ask for \$25,000, they're not going to talk to us. I'm hoping that's a positive thing.

1650

Most importantly, the money is going to the families.

If you go down to the government savings, I calculated the numbers. These numbers are from the government. Using your current budget, you actually can reach almost every child on that wait-list immediately, rather than having them sit and wait.

I'm going to skip over to the overall results on page 5. The results of doing this would be:

- a minimal to no wait-list;
- accessible to everyone regardless of socio-economic status;
- earlier intervention most likely results in more effective therapy;
- an effective professional program is more readily available due to CASPA;
- everyone receives the same amount of money and time so no one is discriminated against;

—depending on how parents spend the money, home-based therapy or in-centre-based, the money can go quite far;

—families get a real choice of their programming, provided that their choice is licensed;

—CASPA ensures professional standards or professionals and centres;

—all children are discharged through a transparent, ethical standard;

—no pressure for anyone to make the wait-list move;

—everyone is treated the same;

—more children are likely to reach their individual potential and earn the option of attending a regular classroom setting without requiring assistance, thus saving taxpayers money; and

—families receive choice and can make the decision of which program is best for their situation.

Below that, we've got some examples of other provinces within the country that are already using this method. One thing I will highlight in the numbers: When I calculated it, using the 3,100 children who are diagnosed on the list, if you divided that up it would result in about \$53,000 per child per year, right from the get-go. I know that some of you are probably going, "That's not enough for a full IBI program. Some of them can cost upwards of \$70,000." But I think if you can reach the kids early enough, you're also giving parents the option to go to work and possibly kick in the difference, whereas right now, most of our moms have to stay home to take the kid to therapy or wait while they're sitting on a wait-list because there's no one to look after them.

Those were my main points.

Is this going on or off or is it just me?

Ms. Deborah Wyatt: I think you get too close to it.

Ms. Jennifer Wyatt: Oh, okay.

Ms. Deborah Wyatt: Jen and I would both like to just say we're very grateful to all of you for allowing us to come and speak to you today. We think it's wonderful that this committee has been developed because we do think that all of us working together is really going to make a difference for these families, and we both feel if there's anything more we can do for you, we're more than happy to help make this the best it can be for these families.

The Chair (Mrs. Laura Albanese): Okay. We'll start with comments. Mr. MacLaren.

Mr. Jack MacLaren: Thank you. It's great to see you here, Jennifer and Deb. We've gotten to know each other fairly well. You've come to my office to talk about autism, to talk about TIPES and to talk about CASPA. Beyond that, we've had chats with Dr. Sherman, we've been to Queen's Park, and you've met with Christine.

You've put some time into trying to do a better job treating kids with autism and helping the families of Ontario. There are a few roadblocks along the way called "government," "DSO" and things like that, so I'm going to ask you some tough questions here.

We know you do a great job, because the parents tell us. They tell us that the kids whom you treat are doing

better; they're improving. They run into the money problem because you can't do it for free. You do train people, so you obviously have well-trained educators or you wouldn't get the good results that you do. I think I heard you tell me one time, and maybe you could comment on this, that once you get these people trained, you're not, unfortunately, able to pay the higher wages of, say, CHEO, which offers the direct service option. You lose them to CHEO sometimes. Basically you do the hard work of training the people and they basically steal them from you with higher wages. That's one question.

The Chair (Mrs. Laura Albanese): Is that a question or a statement?

Ms. Deborah Wyatt: Is that a problem? You want to know if that's a problem? Yes.

Mr. Jack MacLaren: Go ahead.

Ms. Deborah Wyatt: We've been fortunate. A lot of our staff does stay with us, but we definitely do compete with government agencies who have higher salaries, usually because they have—what's the word I'm looking for?—unions in place.

Mr. Jack MacLaren: Yes.

Ms. Deborah Wyatt: So that is a problem for us, yes.

Mr. Jack MacLaren: At one time, you were telling me how many kids you treat and what your budget is and you were comparing it to CHEO, so I'm going to ask you to give us those numbers, if you would.

Ms. Jennifer Wyatt: We've serviced over 150 families in the last eight years. To give you an exact—I don't really know. Our operating budget has never been more than \$1.5 million and we've serviced all those children. Now, granted, they are not necessarily doing 30 to 40 hours a week, because it's whatever the parents can afford.

The government program: I'm not really sure on the exact numbers of that; you'd have to check. I think they are closer to \$7 million or \$8 million, possibly. I don't know. One of you would probably know this better than me. I'm sorry; I don't know.

Ms. Deborah Wyatt: I think the audit actually has a stat in there on how much more it is to fund the DSO provider, so I think maybe that's the best resource.

Ms. Jennifer Wyatt: I had seen a document that said \$14 million, but I can't tell you specifically what was in that.

Mr. Jack MacLaren: Basically, I recall you telling me you treat more kids better for less. You don't have to answer that.

Ms. Jennifer Wyatt: I was going to say, I don't think we can say that.

Ms. Deborah Wyatt: No, I don't think we would ever say that, plus we offer a different—I mean, we don't really want to be comparing to them, because we've never worked for them; we haven't worked with any of their children. They also offer, I believe, a different form of therapy than what we do, so I don't know if it's really that comparable. But I do know, when you look at the audit, that it is more expensive to fund—it seems that

17 JANVIER 2014

way—a government-funded agency versus giving the money directly to the parent.

Ms. Jennifer Wyatt: Yes, that's true.

Mr. Jack MacLaren: Okay. Anyway, thank you for all the good work you do. Thank you for coming forth and working on trying to make things better.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Thank you. Your enthusiasm is catching, so thank you for that. A good note to end on for today.

I was trying to follow along to see where the savings actually were, but it's the direct funding model, number one, and, number two, it's salaries. Is that where you would say, if you looked at the two issues that are different between you and the government?

Ms. Jennifer Wyatt: Yes, and I think some of the savings goes beyond just the provincial level too. I was watching on the news last night that Canada spends about \$51 billion a year on individuals who are on stress leave because of anxiety and what have you. I think this relates to that in that most of my parents are home on stress leave.

Ms. Cheri DiNovo: Oh, yes. I'm not even talking about other costs, but just the direct costs of the IBI treatment that you provide.

Do you know, per hour, what you are paying therapists versus what the DSO therapists, for example, are being paid?

Ms. Deborah Wyatt: I don't know that. I'm not sure.

Ms. Jennifer Wyatt: I know that their—well, actually, I don't even know what their current salaries are. I know that it's obviously more than what we're paying, because people are motivated to go there. They have a union, right? We can't compete with a union.

Interjection.

Ms. Jennifer Wyatt: Yes, I know it's less. It depends on their qualifications, how long they've been with us. Obviously, we do have a chart identifying that. It's usually—I don't know if I should say—

Ms. Deborah Wyatt: It depends on education, their background. We do what we can to support our employees, obviously, because they really are—

Ms. Jennifer Wyatt: Fabulous. They do the work every day.

I can tell you that the most for an instructor-therapist is—I don't even think it's anywhere near \$50,000. I know that they are going there to start above that. I have no idea what they get.

Miss Monique Taylor: One of your recommendations is about regulations, training, and making sure that there is government structure. I think that's a really important piece that I don't believe we've really heard about around this table, of regulating that sector: very important. Benchmarks: How are you determining your benchmarks for success?

Ms. Jennifer Wyatt: Wait. Are you referring to the benchmarks that the DSO has in place or are you talking about—

Miss Monique Taylor: I'm talking about IBI training. How are you determining when they are reaching the

levels that they should be reaching, and discharge? When do you know enough is enough?

Ms. Deborah Wyatt: Every child who comes through our door has a program that is catered to their individual needs. We do have assessments which I know are commonly used among the government-funded agencies as well.

One of the resources we use is called an ABLLS. There's also some other curriculum we'll put in as well called the Carolina Curriculum. There's a psychologist who is involved as well. We also use the testing to make sure that they're progressing correctly. And then, when the ABLLS is pretty much coloured in, that's a good sign that they're ready to transition into school.

The problem we're faced with right now, though, is that a lot of these resources are meant for people who are up to the age of six. They're assuming these things are going to be done, so that when they get into grade 1, they'll be more successful with the transition. But we're finding we get a lot of kids when they're older.

I do think that these programs can be effective. The children that we have received at the age of two are the ones who are into the school system right now. We might support them with a couple of hours of more like tutoring right now, to help them with some of the academic skills, but they might be down to paying for five, six hours a week because they did intervention at 25 to 40 hours a week, starting at the age of two.

Regardless, if they come in at six, we're going to be looking to have all of these goals met before we're going to transition them out, because I feel that if we transition them out too early, we're not doing justice to them or the family, really.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter or Ms. Wong?

Ms. Mitzie Hunter: Yes, Ms. Wong is going to do it.

Ms. Soo Wong: Thank you very much for your presentation and for your passion about this topic. That's really refreshing, as one of our last witnesses.

I'm particularly interested—on page 3, you talked about an outcome-based approach. Am I hearing that if we consider, as a government, adopting what you suggest, it will reduce the wait time?

Ms. Deborah Wyatt: If these figures are correct—

Ms. Jennifer Wyatt: Yes.

Ms. Deborah Wyatt: —which is what we got from the government.

Ms. Soo Wong: Okay. My next question here is, what's your organization's relationship with the local school board? Very clearly, if you start the early intervention, it feeds back to JK/SK. Can you share with us your relationship with the local school board and any activities you're currently working on?

Ms. Jennifer Wyatt: I can probably tell you that as far as the school board goes, it's kind of hard to say. We find it's more that it depends on the school and the principal. There are lots of schools where the principal invites us in, and there are no issues. Then there are other schools where it's almost impossible. We'll request in

September to go in, and it's May before we're sitting around a table.

Ms. Soo Wong: Thank you.

Ms. Deborah Wyatt: But I do want to say that we are very much looking to work with the government agencies.

Ms. Jennifer Wyatt: Yes, absolutely.

Ms. Deborah Wyatt: I don't think you can say one is better than the other. It's just a matter of us all working together.

Ms. Mitzie Hunter: I just wanted to clarify: Do you use IBI treatment?

Ms. Jennifer Wyatt: Yes, we do.

Ms. Mitzie Hunter: Okay. What treatment does the DSO use? You said it was—

Ms. Deborah Wyatt: It is IBI. It's just the model that we use. There are a few out there. I don't know if you've

heard of the Denver-Colorado model; there's the verbal-behaviour model. We personally use direct instruction. It's a model that has been around—I believe it has been the longest—since 40 years ago. One of the psychologists that we happen to work with often, he just believes that you don't recreate it. If it's effective, then we're going to use it. We seem to see really great results with it. In fact, I have yet to see a child not make progress. That's just why we've chosen to go with that model.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation, which concludes also our day here in Ottawa.

For the committee members, I just want to say that we are recessed until Monday, January 20, at 9 a.m. in Toronto. We're adjourned.

The committee adjourned at 1703.

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CONTENTS

Friday 17 January 2014

Developmental services strategy	DS-381
Ms. Donna Thomson	DS-381
United Families of Eastern Ontario	DS-384
Ms. Suzanne Jacobson	
Ms. Jocelyne Brault	
Ms. Amanda Telford	
Fetal Alcohol Spectrum Disorder Group of Ottawa	DS-387
Ms. Elspeth Ross	
Ms. Barbara Sabourin	
Multidimensional Assessment of Providers and Systems	DS-390
Ms. Hélène Ouellette-Kuntz	
Dr. Virginie Cobigo	
Ms. Joyce Rivington	DS-394
Ms. Iman Seifeldin	DS-397
Department of Psychiatry, Queen's University	DS-399
Dr. Bruce McCreary	
Dr. Muhammad Ayub	
Dr. Jessica Jones	
People First of Ontario	DS-403
Mr. Kory Earle	
Ms. Anne Rahming	DS-407
Ontario Residential Care Association	DS-410
Mr. Len Goddard	
Ms. Margo Babe	
Ms. Tina Kokkinos-Marins	
Ottawa-Carleton Association for Persons with Developmental Disabilities	DS-413
Mr. David Ferguson	
Mr. Bill Cowie	
Ms. Bonnie Dinning	
Family Alliance Ontario	DS-417
Ms. Cindy Mitchell	
Families Matter Co-operative	DS-420
Ms. Miriam Fry	
Ms. Nancy Brodie	
Ms. Karin Steiner	DS-422
Ms. Linda Nilson-Rogers	DS-425
Mrs. Cora Nolan	DS-427
Hub for Beyond 21 Foundation	DS-430
Ms. Jane McLaren	
Ms. Andrea Stadhard	DS-433
Partners for Mental Health	DS-436
Mr. Jeff Moat	
Mr. Michael Dixon	
Ms. Janet Osborne	
TIPES; CASPA	DS-439
Ms. Deborah Wyatt	
Ms. Jennifer Wyatt	



DS-14

DS-14

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Monday 20 January 2014

Journal des débats (Hansard)

Lundi 20 janvier 2014

Select Committee on Developmental Services

Developmental services strategy

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Stratégie de services
aux personnes ayant
une déficience intellectuelle



Chair: Laura Albanese
Clerk: Trevor Day

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON
DEVELOPMENTAL SERVICESCOMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Monday 20 January 2014

Lundi 20 janvier 2014

The committee met at 0902 in committee room 1.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning. I call the Select Committee on Developmental Services to order. We are back in Toronto after a week of travel across Ontario, and we're back to the urban setting with the congestion, getting started a couple of minutes late.

DEVELOPING AND NURTURING
INDEPENDENCE

The Chair (Mrs. Laura Albanese): In any case, we want to call up our first presenter this morning from Developing and Nurturing Independence, DANI for short. Please come forward and take a seat. You will have up to 20 minutes for your presentation. If time permits and it should be less than that, that will allow for questions and comments on behalf of the members of the committee. Please start by stating your name and title, and you may begin at any time.

Mr. Rudy Barell: My name is Rudy Barell. I'm part of the junior board at DANI.

Ms. Kathy Laszlo: Hi. My name is Kathy Laszlo. I'm the founder and co-director of DANI.

The Chair (Mrs. Laura Albanese): Welcome.

Mr. Rudy Barell: Thank you. First of all, we'd like to say a quick thank you for allowing us to present. We understand the time constraints, as you mentioned, so in an effort to be brief, what we will do is provide a general overview of what DANI does and then hopefully accept some questions from you. For a more in-depth understanding of us, we've provided a little briefing. As well, we're making ourselves available to you guys should you feel the need to get more information from us on a personal or one-on-one kind of individual basis.

You'll excuse me; just in order to get all my points to you in the brevity of the presentation, I'm going to be checking my notes occasionally.

DANI was created with an understanding of the current fiscal constraints facing the province of Ontario and the need for the province to create a sustainable option for this sector—i.e. individuals with developmental disabilities and/or cognitive disabilities, as well as physical challenges. Our goal today is to present what we

feel are some suggestions for a sustainable option. It's a model that we're currently using, and it's successful.

Essentially, the way DANI runs is that we train and employ individuals with developmental and/or physical disabilities towards long-term employment within a social enterprise setting. Our individuals are constantly being trained within viable businesses where the businesses are actually earning. They're being trained, the businesses are earning, and then that money gets funnelled right back into the program.

The model is based on something that exists in South Africa, which was researched and visited by Kathy. Kathy took that model and brought it here. That model has actually been in existence for almost 20 years. It's very successful and it continues to grow.

Basically, our long-term goal is to become fully sustainable. Currently, we get a lot of support from donations while the social enterprise dollars continue to increase as the businesses grow. We have received some funding from government for capital costs and renovations on the municipal level, as well as on the provincial level from Trillium—which is a nice thank you we'd like to say, anyway.

The short-term goal is to continue to expand the social enterprise arm of the organization. For that, I'm going to let Kathy go into a little bit more detail on that.

Ms. Kathy Laszlo: There are many unique sides of this organization, and some of them Rudy pointed out: that we are looking to sustain ourselves in the long run. You will see it in our write-up. There are six arms for that social enterprise, as we speak; currently, three of them are working. We are putting them in place in a levelled way, not just because as a business you have to be careful how you plan your business, but also because we have to make sure that the young adults are trained and able to functionally work in these places.

Our goal is not that we put them in just for the sake of being in, but that they are absolutely part of the whole business. We train them in soft skills as well as vocational skills, and then they are part of the whole organization.

The most successful arm right now is our catering arm. We actually just, in the last three days, hosted 600 people in our facility over three functions. Thank God we also made some money, as well as gave the opportunity for these young adults to show what they can do.

The other uniqueness of the organization is that it's community-based. We have many, many volunteers helping us out, which helps to lower the payroll; we don't have that many paid employees. The community comes in, and they support us by taking part and ordering from us. As well, they help us to run the whole organization, so it's a win-win situation on many levels.

We involve different groups: senior groups, who are also somewhat in need of a bit of help, and they come and they help us out. In return, they have a place to be when they feel very much needed. We work with schools and university groups, so it's really a very nice community organization.

We're looking at this as a pilot project that we have brought back from South Africa. We are also documenting everything, because we really believe that it can be used all over the city, Ontario and even Canada. The model is really working. We already see returns financially, which we can turn back into our organizational budget. In the long run, that can be even more successful as the business will grow.

The other arm to the social enterprise is an open-to-the-public retail store. We are located in a community centre; we are very lucky that, inside the community centre, there is a concession store, which we also manage. That gives an opportunity to different groups of young adults who are able to interact with the clientele. Through that interaction, in the long run, they are able to take outside, open-market jobs. We successfully have three individuals right now, as we speak, who are paid and employed in the open market. By the way, the social enterprise also pays the young adults who work there, because we believe that if they do the day's work, they should be compensated. We also teach them budgeting skills; it's very difficult to teach budgeting skills if you don't own any money, so it's a very important part of the organization.

The third arm working right now is a gift store. Again, it's a different group of young adults who are able to package some of the big goods going into gifts, and then they are also helping us with marketing. We have some kids who are very good on the computer, so they make up flyers. They're really part of the whole business, not just the manual work.

0910

It is extremely successful on many levels, but there are limitations. The major limitation is in terms of the speed of how we can put in the additional arms of the social enterprise. Especially the limitation is how many young adults we are able to train in any given minute.

I'm sure you can appreciate that even the highest-functioning person with difficulties needs bigger support if you want to train them in a new area, especially vocational training. Therefore, the ratio has to be really high. Job coaches have to be higher. Social workers are needed. We take on young adults who have mental health issues. Social work is a very, very big component.

There is a financial limitation on what we can do and how fast we can enrol these young adults. We researched

that there are many, many more out there who would benefit from being part of DANI. It's a struggle. We'd like to see how the system would work if we would be able to grow a bit faster. Regardless, we are growing, thank God. We've existed for seven years, so I think we've done really great growth in these seven years.

We are serving about 100 families in different ways, not all of them part of the social enterprise. Some of them are younger, and they come from high schools. They stay with us in the transition years. It has proven that those adults who were with us through high school transition into our day program much easier because they are already known to us and they feel much more comfortable. So we also work on the transition part, as well as providing them with co-op placements in our social enterprise.

I can talk about this until tomorrow morning, but the time is limited. So I really would like, if you have any questions—and we brought some numbers here, so that probably needs a bit more studying, but I'm an accountant, so go for it, please.

The Chair (Mrs. Laura Albanese): We will start with Ms. Jones. It's roughly three minutes per party.

Ms. Sylvia Jones: Thanks so much for appearing before the committee. You sound like you are serving a lot of people in a relatively small area. I see, back on page 1, where you talk about your income and stuff—I'm curious as to: What was the trigger that allowed you to start up? You've tapped into a number of programs. You've been blessed with some Trillium money and, obviously, donations. Is the rent being covered in the community centre by the municipality? Are you charged rent?

Ms. Kathy Laszlo: We are charged a lower rent, but we do pay that.

Ms. Sylvia Jones: Who put the initial commitment in, or where did the initial funds come in, to get you started?

Ms. Kathy Laszlo: There is a user fee to every program we run. The parents pay. Every single person is subsidized. We don't have the traditional subsidy format. Everybody is subsidized. Currently, about 33% of the budget is covered by user fees from the parents; 77% has to be somehow brought in. As we speak, right now, it's all brought in through fundraising and some of the money coming from the social enterprise already. The catering arm is already making a profit.

Ms. Sylvia Jones: In year one, it looks like there was seed money of \$250,000.

Ms. Kathy Laszlo: No. The yellow highlighted item is really what we would need to have the growth of the social enterprise really working, the seed money we're actually looking for.

Mr. Rudy Barell: I think the concept here is that, as we were saying, we're growing slowly, but—

Ms. Sylvia Jones: Oh, so the seed money is your ask.

Mr. Rudy Barell: This budget was made for an ask, yes. But the concept here—we're not coming here to ask for anything. We're showing what could happen with seed money, i.e., we know that the government is looking

to make intelligent investment in—you guys are already spending tons of money. So rather than spending it on—I refer to it as a black hole, and I apologize, because the truth is, more and more people are being identified as with needs, and that just means more money that needs to be spent. This way, we're seeing—

Ms. Sylvia Jones: Well, actually, right now, it just means more waiting lists.

Mr. Rudy Barell: Sure.

Ms. Kathy Laszlo: Exactly.

Mr. Rudy Barell: So either it's more money, or people aren't being serviced in the way that they need to be. Essentially what we're saying is that we're going to continue to grow at our incremental level, but in order to service more people, as you were saying, a smart investment—that's sort of what that shows.

Ms. Kathy Laszlo: What the yellow highlighted area shows is really a decrease of the need of money in the upcoming five years, because the social enterprise will replace this amount. Initially, any business you run needs a start-up, so when we call it "seed money," it's really a start-up cost to the business to run as it should, service as many young adults as it should, and start to make money so that in five years it can be phased out. We can call it government support; we called it seed money. Basically what we show here is that in five years, the government support can actually be lower and lower and lower and disappear, as opposed to today's traditional funding, where it's ongoing and needs to be increased to keep up with services. What we show here is a decrease.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. DiNovo:

Ms. Cheri DiNovo: Yes, thank you, and thank you for the presentation. It sounds amazing. Thank you for all the hard work that you've put into it, I'm sure with little recompense.

I had some of the same questions that Ms. Jones had, so now that you've explained some of the figures, what is the user fee that you charge parents per participant?

Ms. Kathy Laszlo: In dollar amounts?

Ms. Cheri DiNovo: Yes.

Ms. Kathy Laszlo: It's depending on how many days somebody is in the program and which stream they are taking. There are three different streams at DANI. One is the vocational stream, where we teach them the skills and then they eventually work inside internally. Then there is a stream which is called Bridges to Transition. These are young adults who are candidates for independent living. We can call them the highest-functioning ones. They are the ones who start to work in the open market. Then we have the life skills groups: those young adults who somewhat take part in the vocational training, but very limitedly because of either their needs or the family's needs. We do not refuse somebody just because they're not going to be the best-ever worker in the catering business. The fee is dependent on which stream somebody is in.

The highest fee a family would pay is \$1,500 a month for full-time, five days a week. Keep in mind that we provide all food, from snacks to lunches to anything—to drinks or transportation, and all the training and anything needed—any device, any modification to any work environment.

Ms. Cheri DiNovo: And what is the lowest? What is the range then?

Ms. Kathy Laszlo: The lowest range would be the young adults who are fully working. They pay \$20 per day—it's really for their upkeep—but they get paid by us, according to how much they work and which arm of the social enterprise they work in.

Ms. Cheri DiNovo: Right. So when I'm looking at schedule A, when you're looking ahead: If the seed money—the \$252,000—doesn't come from government, you're planning on fundraising all of that?

Ms. Kathy Laszlo: We will fundraise some of that. We just had a very successful gala event yesterday honouring the mayor of Vaughan. We come up with ideas. But I also have to tell you: What happens is that the growth is going to be slower and we're going to take fewer kids than we could. We consider this as really a last option because right now we accommodate anybody who comes to us and we are able to support them.

You should also know that I'm a parent of a special needs child. My son was the first person at DANI. DANI is named after him; he is Dani. If I wear the hat of a parent—it's the most horrible thing ever when you find a program which you absolutely love and you know it's great for your kid and then they turn around and tell you, "I'm sorry; it's full." As a parent, nothing worse can happen to you. We tried to stay away from that. As long as we can support the young adults, we would like to take them, but unfortunately, there is a limit, financially speaking.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair. Thank you so much for your presentation. I'm just looking at the Bridges to Transition program. You also mentioned, Mr. Barell, that investments are required. What types of investments would you say would assist the social enterprise?

Mr. Rudy Barell: I'm going to let you handle that one, if you don't mind.

Ms. Kathy Laszlo: Right now, we're not really looking into capital dollars. We are very happy that Trillium helped us. In about a month, we're going to open our next social enterprise arm, which is going to be a year-around heated greenhouse. That's with the help of Trillium.

What we need is really operational dollars to be able to hire additional job coaches, and we desperately need a full-time social worker.

0920

Ms. Mitzie Hunter: In terms of the participants gaining employment out in the marketplace, can you talk

about your experiences there and what you're seeing in terms of the uptake—

Ms. Kathy Laszlo: Absolutely.

Ms. Mitzie Hunter: —as well as the retention of those jobs?

Ms. Kathy Laszlo: We do have a very good relationship with businesses in our area. Two of the young adults work at Red Lobster. One of them working there started out as a co-op student from high school. When he ended up at DANI, we kept this workplace and they kept him on, so this is his third year there. I would say that's quite sustained. We added another young girl to that same workplace, and then there's another individual working in a different restaurant.

Sustainability: I tell you, I really believe it's sustainable as long as there is—there has to be support. Even down the road, if somebody can work fully, trained in any given way, there has to be a buffer zone. If you want to be successful, there has to be a buffer zone.

These individuals have their issues. It's never going to go away; it's never, ever going to go away. If we want them to be successful, we have to be there for them. If there is an issue coming—and let's face it, they work in the lower end of the spectrum, right? They usually have very, very start-up positions. The person who supervises them is also not a very high-up management position. They're usually not overly trained on how to deal with these individuals. There arises an issue when something is not done properly. The manager yells at the kid. The kid is not going to go back, because they don't understand that this is the boss and they have to do it. So we have to be there for them—and for the employers as well, to have sensitivity training, to teach them that these kids are fantastic but they might be a little bit different.

We have to be there to modify the work stations. We have kids working in packaging plants, where they package socks. We have my own son, who is visually impaired. He can work there, but he needs different lighting, so we had to make sure that we can provide that. The workplace was amazing; they never even let us pay for it. They put it in, and he's fantastically successful. It's the second year he's working there—amazing. It's not just the fact that he's really doing the job, but can you imagine, when he's coming home, how proud he is of himself that he went to work like his siblings? He is just like anybody else. The satisfaction is fantastic.

We have young adults who, until now, were sitting at home doing absolutely nothing, and they work in a restaurant. They come up to me and they say it's the first time ever that somebody looked up at them instead of down at them. Can you imagine? You can't put dollar figures on this; you really can't.

This boy is very high-functioning. He comes and goes on his own. He is TTC-trained. He's a fantastic guy. You just have to give him the opportunity to be there. Then he gets a tip, and it's like \$2, and it's the world to him that he got \$2 on his own. It's not like they paid him; it's that the customer was happy and they tell him how good he's doing. It's amazing. He wants to come back, and I put

him only for four hours and he wants six hours. It's amazing, what happens there.

I really think that they have a rightful place. Yesterday, we had 300 people there, all walks of life, at that gala—all walks of life; different communities; all kinds of people. The tears in their eyes—we showed a video presentation about what the kids are doing. You can't really put a price tag on it. It's really successful, and this is something which is proven.

I don't believe, by the way, that government should just give the money year after year and year after year, regardless of what you're doing. We've seen, as a parent again—believe me, my son went through many, many places throughout his 27 years. You can't have a place where you get the government money every single year, regardless of what you do. I really don't believe in this.

I think that, including ourselves, we have to prove ourselves. It's not like we're asking for the money and you should never return to see what happened with the money. I want you to come. I want you to see that this money is working, because that's the only way you would see the value of supporting us in our next adventure. I'm a dreamer, right? I already have other ideas.

The Chair (Mrs. Laura Albanese): Thank you—

Ms. Kathy Laszlo: But if I want to come back to you, I have to prove that I can do it, that we can do it. It's a team, and I believe in this. We all have to show that we can actually do it, and what happens with every single dollar. Again, I'm an accountant, so every single dollar is accounted for, and it's very important.

I would love you to come and visit us, by the way; you're very welcome. We make a very good cappuccino.

The Chair (Mrs. Laura Albanese): Thank you very much for the invitation.

Interjection: Send us your address.

Ms. Kathy Laszlo: It's right here. The address is on.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation this morning.

Ms. Kathy Laszlo: Thank you very much for your time.

The Chair (Mrs. Laura Albanese): We really appreciate learning more about DANI. Keep up the good work.

Ms. Kathy Laszlo: Thank you. Sorry if it maybe took too much time.

The Chair (Mrs. Laura Albanese): Thank you.

MS. LAURIE WATT

The Chair (Mrs. Laura Albanese): We'll now call on our next witness: Laurie Watt. Good morning to you.

Ms. Laurie Watt: Good morning, Madam Chair and members of the committee. My name is Laurie Watt. By profession, I'm a newspaper reporter. I'm here to share my daughter's story. This is my daughter Rachel.

The Chair (Mrs. Laura Albanese): Wonderful to meet her.

Ms. Laurie Watt: You won't be able to see her picture, but anyway, here she is. That's her high school graduation picture.

Anyway, by the time Rachel was two, she didn't speak—not a word. I went with Rachel to the Barrie Parents Club, a drop-in play program run by our local Community Living agency and a precursor to what's now our Ontario Early Years Centre. I hoped that through interacting with other children, Rachel might begin to speak. That winter morning on which I dared to venture out was pivotal. Rachel darted around the centre and didn't really interact with anyone or focus on play. But a staff member there said, "Bring her back. She belongs, just as much as anyone." Every day, I hear that staff member's voice.

I went home and began fighting for speech therapy. I made a call to the Royal Victoria Hospital's speech therapy department and begged for someone to call me. We had been on a waiting list for months. I asked for a recommendation for a book or a course to take, anything to help me help my daughter talk.

Someone called me back. She was Mary Riggan Springstead. Mary is a speech-language pathologist. She was instrumental in getting Rachel placed into the preschool system. Through the preschool system and into the elementary system, through the transition to high school and now the adult developmental services system, I've had the good fortune of encountering real stars like Mary—wise people who cared, who believed in Rachel and who fought for her. If it wasn't for these people, I don't know where Rachel would be today.

As I endeavoured to get Rachel the help and care she has needed throughout her life, I have found there are a series of cliffs off of which people fall. The preschool system is critical. Mary got us in. I worked with resource teachers in an integrated preschool to implement a speech therapy plan, and together we got Rachel talking by the time she was five.

We looked at her sensory issues and implemented an occupational therapy program to help her even more. The benefits Rachel received during these formative years were immense. It's my understanding that resources are tight in Simcoe county and there are waiting lists for infant development and resource teacher programs. Early intervention is key, as Rachel's brain shows that their brains are most malleable in those early years.

However, going from the preschool system to the school system—that's a cliff. Services and supports drop dramatically. At the time, Ontario didn't have the ABA program. It took us six and a half years to get her diagnosis. Had that program existed then, Rachel would have aged out. We were lucky to get her diagnosis at the Hospital for Sick Children.

Thanks to Patricia O'Connor, an integration resource teacher, I got Rachel settled in kindergarten and later into a specialized autism pilot program. Unfortunately, the Simcoe County District School Board deemed it too expensive and cancelled it after two years despite having \$10 million in unspent special education reserves. The school board went on to discourage and scatter some of the best-trained teachers and support workers, like Pat O'Connor.

Keeping the school board focused on my daughter's needs was a battle for years. I had to keep a vigilant eye on her IEPs and how they were being implemented. But after I had another child and was unable to keep as keen an eye on the school, I soon suspected Rachel's seizure medications were being inappropriately administered. She was sleeping her school days away in her later elementary years, and I knew it was time to change school systems.

Then I met another star, Erin O'Brien, a special education resource teacher at St. Peter's Catholic high school in Barrie. Rachel calls Erin her best friend. St. Peter's took Rachel in and for six years Rachel thrived and developed. This was an incredible blessing for us, as Rachel's father and I had decided just a few years earlier to place Rachel into Daffodil House Children's Residence, a private group home just down the street from St. Peter's, in hopes that routine and treatment would build her skills and keep our toddler son safe—Rachel's seizures and sometimes violent behaviour were a threat to his safety. We did this with the help of individualized funding.

0930

While on a visit to St. Peter's with her Grade 8 EA, a passer-by called police to express concern about the way Rachel was being treated by her EA. Days later, just days before Rachel was leaving her elementary school, an officer called me to ask whether I'd like to lay charges. I opted not to, because I felt had to focus on the next phase of Rachel's life, the seven years in high school which would get her ready for the adult world.

I am grateful for these stars like Mary, Patricia and Erin. They kept Rachel out of real harm in the Simcoe County public education system that has made headlines around the world with its inappropriate use of rugby blocker shields in a specialized autism class—which is, by the way, where the board suggested that Rachel be placed.

The health care system is another story. Getting appropriate care for Rachel has been a struggle from the get-go. She has had complex seizures, sparked by her immunizations as a baby. According to SickKids, they played a major role in the development of her seizures and her autism.

Memories of Christmases past include being sent home from the Royal Victoria Regional Healthcare Centre because a one-to-one nurse couldn't be found and the hospital didn't want to accept the liability of admitting her. So, instead, I—her journalist mother, armed with needles and Ativan—would be the neurology nurse.

Hospitals never like admitting Rachel, because of her behaviours. She is difficult. Getting her autism diagnosis—which helped and sometimes harmed her—was a struggle too; as I mentioned, it took until she was six and a half.

Getting in on research at SickKids was our ticket to better care, but through the years, this has been stressful and expensive and was indeed a factor in killing my marriage, as time demands ate away at our finances and

our relationship. But Rachel benefited, and that's all that really matters.

At our local hospital, Rachel had become "the girl who always seizures"—at least, that's what the emergency nurses called her. I remember a day in 2011 when Rachel broke her nose after falling face-first during a seizure onto a cold-air vent at the Daffodil home during a seizure. Rachel was just turning 18. I can still hear the emergency doctor saying, "For people like your daughter, it would be pointless to fix her nose. It'll heal eventually."

"People like my daughter"? An 18-year-old woman with her whole life ahead of her? An 18-year-old woman who has already encountered more than her fair share of barriers? I demanded to see a plastic surgeon, who said, "Oh, yes, I can fix that." Thankfully, she has a better nose now, because she had broken her nose during a severe head-banging phase when she was about five.

We discovered through that nose incident that oversight in the children's system isn't sufficient. A year later, the group home's licence was suspended, and I don't have details as to all the reasons why. The need to get Rachel moved out of that home was both good and bad. It made Rachel a priority at the DSO's regional table. It got her a placement at Camphill Communities in Angus, but it opened our eyes to the lack of quality and accountability in the adult system.

Within months of Rachel getting her placement at Camphill, her cellphone was taken away, the land line in her apartment was removed, and the agency began picking fights with school staff. One day the school called me at work to tell me they'd received a call that Rachel wouldn't be returning to school. When her father and I fought that, allegations of bullying by school staff emerged. Although details were scanty, it was an issue of control. Camphill's executive director told me to be grateful and to basically stop advocating for my daughter, whom I could not drop out to see nor whom I could call.

Rachel's ability to carry on conversations diminished dramatically. Her obsessive behaviours became more intense. Then, one day, I'm asked to talk to a psychiatrist about adding more drugs to Rachel's handful—literally a handful—of anticonvulsants and antipsychotics. I said no. I recommended that group home staff follow the OT and speech programs that had been so successful in the past.

More than a year and a half after being admitted to this agency's care, her father and I still don't have an individual support plan, and such a plan shouldn't have been too difficult to create, since we'd given Camphill several of Rachel's IEPs and occupational therapy reports. And, I might add, her father and I don't know what her days look like, what activities she's enjoying most or making the most progress in. That not only hampers our ability to have meaningful conversations with her; it prevents us from supporting or encouraging her on her ISP goals. At Camphill, parents are definitely not partners.

Meanwhile, the skills that many of us—Mary, Patricia and Erin—worked so hard to build are diminishing. My daughter's quality of life is diminishing. It feels like I'm losing Rachel to a cult. Not only that, Camphill has the right to remove Rachel from care should they deem her too much of a burden, with no recourse and no alternate placement, with only six months' notice. I am told I should be grateful.

What do we learn from all this? What wisdom can I offer you? What recommendations would I like to see in your report?

(1) Ontario's quality assurance standards—and they are wonderful; I've read them—aren't being respected or enforced in schools, hospitals and group homes. They need to be enforced, and compliance should be mandatory.

(2) Institutions that Ontario had the vision to close, such as the Huronia Regional Centre, never reopen, that the abuses in them are never repeated and that institutional segregation and treatment—which doesn't have to happen in a building; it can happen in other places—should never be allowed to take root and grow again.

(3) We have a developing developmental services system. Agency leaders and workers need clear direction in terms of the transition from the IEP to the ISP.

(4) For young adults with autism, like Rachel, ensure that they're engaged in meaningful work, work that embraces their interests and abilities, and not slotted into spots for the convenience of the organization.

(5) Insist that all ministries work together during and after transition of young people like Rachel from one level of education and care to another to create a seamless transition at a very challenging time.

(6) Develop a case management system that supports individuals and values family input.

(7) Create structured days for individuals like Rachel, days that include proven therapies and strategies and the teaching of independent living skills and activities that are meaningful, whether paid or volunteer. Enhanced investment is needed, not an additional red-tape process such as a DSO, which can keep families away from services, which, when they get them, can be limited.

Ontario has the idea and the ideals. Through years of volunteering with Simcoe Community Services, I've been to Community Living Ontario and even the national community living conferences, where I've seen people with special needs gain their voices. Our communities have become more accepting.

I'll leave you with a documentary made last fall—I gave it to your Clerk—that shows how some Barrie-area adults tell their stories. They show why the commitment to inclusion, rather than institutionalization, is worth it.

We need to find ways to ensure that Ontario's quality assurance standards are not only respected but enforced. Much more oversight is needed. Otherwise, it's just a matter of time—months, not years—when we will see the era of the institutions we have just closed re-opening. We must be diligent in ensuring that institutional thinking and treatment never be allowed to recur. That's not the

way we live in Ontario, where everyone belongs and where we are better together.

Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you for your passionate presentation. About two minutes each. Miss Taylor?

Miss Monique Taylor: Thank you so much for being here with us today and for the efforts that you put into this presentation. It's appreciated.

I could be wrong, but I don't recall hearing at this table the request for quality assurance.

0940

Ms. Laurie Watt: You do have quality assurance standards; they just aren't respected.

Miss Monique Taylor: Like I said, I'm pretty sure that you're the first person who has brought it up, saying that we need further oversight on that because it's just not happening in the homes. That was a really good point that I'm happy you brought forward.

You mentioned transition and better transition. What was your experience when your daughter was transitioning out of high school?

Ms. Laurie Watt: It was rather rushed because of the group home licence—the children's licence suspension.

Rachel went to the DSO table, and she quickly got a placement; she was a high priority. But then, it seemed, they moved her in and they put her in the home and thought, "No, this really isn't where she belongs." They suspended her for two months.

My husband and I—well, he's my ex—basically managed her between our two places, with complex care funding. They moved her into a different home within Camphill Communities. They said, basically, that her anxiety was too much. They took away her cellphone; they took away her land line. They restricted our visits. They said that visiting her family was too stressful. We basically lost touch with her.

Miss Monique Taylor: So it was a decline, once you put her into that home.

Ms. Laurie Watt: It was a dramatic decline, and the decline continues.

Miss Monique Taylor: Have you filed any complaints or anything—

Ms. Laurie Watt: I've spoken to the Ombudsman. The Ombudsman is preparing a report on services for people with autism. I'm hoping that they'll be able to use some of my feedback.

The Ombudsman has suggested that I speak directly to my regional office of the Ministry of Community and Social Services, but I hesitate in doing that because I'm really afraid that Camphill will pull out the six-month clause, and then where will Rachel be?

Miss Monique Taylor: So you're afraid to make—

The Chair (Mrs. Laura Albanese): This is the last question. Sorry.

Miss Monique Taylor: I'm really sorry to hear that.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter.

Ms. Mitzie Hunter: Ms. Watt, thank you for being here today and sharing your story as well as Rachel's story over these many years. It clearly highlights the need for better transition, and also coordination amongst ministry areas. It's something that we have heard, during the course of our listening, right across the province. We are definitely receiving that information and taking it into consideration as we prepare our recommendations to improve the system and to strengthen the system. It's meant to be across a lifetime for people with developmental disabilities.

I do want to assure you, because you raised it a couple of times in your presentation, regarding the past and the institutional era, that that is behind us. I know that our Premier has stood in this House and offered an apology on behalf of the government, and all party leaders did the same.

Our focus moving forward is on inclusion and better integration within communities. That's something you also refer to here in terms of: Are communities becoming more accepting? That's something that we believe as well, and want to see that happen. There are some good examples that are happening, but we need to see more of that.

I don't know if you have any further recommendations along those lines in terms of improving inclusion.

Ms. Laurie Watt: Institutional thinking doesn't just happen in buildings; it can happen within organizations. Camphill does receive government funding, and therefore it is a placement that is given out at the DSO table. But clearly, it is an institution, and I think that there desperately need to be quality standards that are met, as well as much closer oversight by the Ministry of Community and Social Services. I know that the executive director of Camphill talks with the regional office.

Rachel does require a lot more money than your typical resident, but I don't think the money is necessarily being used appropriately or well.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Elliott.

Mrs. Christine Elliott: Thank you, Chair, and thank you very much, Ms. Watt, for being here today and sharing Rachel's story. You've had many bumps in the road over the years, and it's quite unfortunate. Your story is very similar to what we've heard from other people, that the transitions are very difficult.

One thing I did want to follow up on with you is the education system for your daughter. Is she still in school? How old is she now?

Ms. Laurie Watt: Rachel is 20. She could have spent this last year in high school, and we had hoped that she would spend the year in high school. But Camphill made the previous year of school so difficult that we had to pull her out. We tried to transition Rachel out by creating a co-op placement for Rachel, but Camphill didn't abide by or respect that agreement either.

Mrs. Christine Elliott: So what is she doing now? Is she just at Camphill?

Ms. Laurie Watt: I don't know what she does. The great irony of all this—and I told Camphill's executive director—is that my parents knew more about what I did when I went to journalism school in Ottawa, which was six hours away from where I grew up, than I know about what Rachel does half an hour away, and Rachel is a vulnerable adult.

Mrs. Christine Elliott: Well, that definitely should not be. We will certainly be taking all of that into consideration for our deliberations. Thank you very much for being here.

The Chair (Mrs. Laura Albanese): We want to thank you for your presentation this morning. You've brought forward some important recommendations. We hope that through our work here, we will be able to improve Rachel's life and the lives of others like her. Thank you very much.

Ms. Laurie Watt: Thank you so much.

PEEL PLANNING GROUP

The Chair (Mrs. Laura Albanese): I just want to advise the committee that our 9:40 has cancelled—Prince Edward Learning Centre—but our 11 o'clock is here, and they're ready to go.

Interjection.

The Chair (Mrs. Laura Albanese): Yes. Okay.

Ms. Leanne Baldwin: Thank you. We appreciate it.

The Chair (Mrs. Laura Albanese): Thank you. We appreciate the fact that you're willing to go earlier.

Ms. Leanne Baldwin: No problem.

The Chair (Mrs. Laura Albanese): So just settle yourself in. You're from the Peel Planning Group; is that correct?

Ms. Leanne Baldwin: Correct.

The Chair (Mrs. Laura Albanese): Welcome to our committee this morning. You'll have up to 20 minutes to make your presentation. Should it be any shorter, we will have time for questions and comments from members of the committee.

Ms. Leanne Baldwin: Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you. Whenever you're ready, you can start by introducing yourself, by stating your name and your title.

Ms. Leanne Baldwin: Okay. My name is Leanne Baldwin, and I'm the chair of the Peel Planning Group. Actually, in the 22 years of its existence, I've been the chair for 14 of those 22 years, but not consecutively. In my sort of more full-time role, I have been the manager—different titles over the years—of Peel Behavioural Services since 1979.

I feel that this is very much an honour, to have an opportunity to present to you, and I really appreciate you giving me this opportunity.

The Peel Planning Group provides leadership in a systemic and strategic evolution of developmental services in the region of Peel. Comprised of representatives from a number of ministry-funded community-based service providers, it has an established track record of

serving an advisory function to the central west regional office of the Ministry of Community and Social Services. In addition to representation from the developmental service sector, the group includes representation from the child welfare and mental health sectors and also family groups.

Peel region's population continues to mushroom at a rate over double that of the province of Ontario. If the growth rate continues at 11.8%, Peel's population will grow by 150,000 between 2011 and 2016, which is the equivalent of adding the city of Oshawa to the region of Peel—or the city of Kingston; take your pick.

It is important to understand that the incidence of developmental disabilities is 2% of the population or thereabouts. That means that as population increases, more and more people are in need of services. Presently, there are approximately 26,000 individuals with a developmental disability in Peel. Approximately 21,000 are over the age of 15, and 14%, or 2,869 people in Peel, are now registered with the DSO for the central west region.

0950

For decades, Peel was receiving approximately \$140 million less, almost half the per capita funding for developmental services, than other Ontarians, and I believe that's very well documented through the Fair Share for Peel initiatives.

While Peel has a broad continuum of services, we have very little depth to them, and we have been creative and efficient with the limited resources we have. These services, however, are woefully inadequate to keep pace with the growing needs and mounting pressures in our region.

It is important to recognize that individuals with a developmental disability face a lifetime of challenge, marked by periods of fragile calm but continuously punctuated with anxiety associated with, "What if or what about when circumstances change?" More and more families are in crisis. Families and individuals languish on waiting lists, and we have even seen desperate families relinquish care of their children in hospitals, at respite homes and at agencies.

We also see young adults being placed in long-term-care centres because the developmental service sector cannot respond. The inadvertent message to families is becoming, "Drop your children or adult children off at an agency or hospital and you will get service." This has caused much frustration amongst families who are playing by the rules by remaining on the waiting lists. Right now, we know that there are 363 people in Peel who would accept residential support if it was offered yesterday.

I've included in your documentation the latest preliminary findings of the DSO for Peel region specifically. Also, I believe the Ending the Wait report documents the extent of the issue.

There are a number of examples in Peel of families organizing themselves and pooling their own resources to respond to the needs of their family members with a

developmental disability, but they can't do this alone. They need ongoing, predictable support.

It is unacceptable that young adults with a developmental disability graduate from the school system with nothing to do and nowhere to go. Parents have had to quit work to stay home with their adult children. Most often, this increases family stress, which can then lead to family breakdowns.

Some 72% of the people seeking services through the DSO were between the ages of 16 and 24 in 2012-13. I asked our executive director of the DSO if the figures were different for 2011-12, when it first opened, because of course a number of people were grandfathered. Unfortunately, the bulk was still in that age group, so it's obviously a pattern.

Parents in Peel and across this province are at a loss as to what will happen to their son or daughter when they're gone. We know of parents in their 60s, 70s and even 80s, some of whom are infirm, who understandably fear for the future of their children. There have been situations where elderly parents have passed away and their adult children now have no one to care for them.

In another role, I'm also the chair of service resolution in Peel. One only has to attend a meeting to hear the heartbreaking stories. We listen to presentations at every adult service resolution meeting that exemplify the crisis mode we now assume is the norm.

Over half of all of the applicants for services through the DSO have only their parents, and possibly one other person in their life, that they can count on for regular support. Individuals with a developmental disability are living increasingly isolated lives. This isolation is also referenced in the Ending the Wait report.

Based on the above, the Peel Planning Group prioritized the development of an advocacy framework in the hopes of raising awareness of the need for new resources and public policy to support adults with a developmental disability to live and participate fully in their community, and to help families care for their family member with a developmental disability. The preliminary report of the DSO relevant to the region of Peel describes the dreams of the individuals we serve, and here we are unable to meet basic needs. This report, as I said before, is in your package.

The relinquishment of care alluded to above was another priority identified. Peel Crisis Capacity Network, which is really a network of agencies providing services to this population from age 11 and up, indicated that, between January 2011 and August 2013, 44 individuals were abandoned; 26 of the 44 were described as having high behavioural needs, and 17 of the individuals were abandoned at a health care facility. The Peel child and youth planning table concurred that this was a significant problem.

Kerry's Place Autism Services took the initiative to examine the issue more closely, and a guide was developed with the intention of assisting professionals who may have a direct or indirect role in addressing the immediate and longer-term needs of complex youth and

young adults who are in crisis due to the absence of a participating primary caregiver, all in an effort to reduce the frequency of abandonment.

Currently in Peel, there are 14 individuals who have been placed on a "pressures" list since April. Of these 14, seven have been confirmed on the ministry's at-risk list. The "pressures" list is made up of individuals who are at risk for homelessness or who may already be homeless and may have aging or infirm caregivers or be experiencing significantly changing needs.

The need for day programs has also been prioritized. We currently have 1,443 people who reside in Peel receiving support from the Passport Program. Unfortunately, there are another 596 on the waiting list, either waiting for more needed hours or simply waiting for hours, period.

What has become really clear is that students leaving the educational system have nothing to do and nowhere to go. They remain at home, and key skills that have been previously mastered begin to disappear. They remain at home, and their behaviours begin to escalate, and families have to alter their lives drastically to provide support in the hopes of averting a more urgent crisis.

Finally, the Peel Planning Group prioritized individuals with a dual diagnosis and the need for a system-level response. You've already heard the data and suggestions provided by Dr. Yona Lunsky, Cathy White from the autism society in Ontario, Dr. Szatmari and others indicating the need for a comprehensive, systemic response across the lifespan for individuals with complex needs.

In reflecting on the above, one is struck by the urgent nature of the needs identified. As a planning group, Peel Planning Group does work well together. We have a high degree of trust and a deep respect for the individuals we serve. We've developed some very creative solutions over the years, but we feel we are now facing a wall and that it has become a humanitarian crisis. The system of supports is so fragile that when one variable is altered, the support system falls like a stack of cards and individuals go into crisis.

As a social service system, we have reduced flexibility. We've been forced to be reactionary versus proactive. We are incapable of meeting the basic needs of individuals. We are constantly dealing with a skewed distribution of the population, and by that I mean the most complex individuals with the highest needs. Where is the preventive component? Essentially the bottleneck in the system is moving down into community supports, and the waiting lists are growing.

What do we need? We need a comprehensive service system that supports individuals across a lifespan. We need better collaboration across ministries and increased flexibility—housing, health, education and social services. We need an integrated response that views the individual as a whole and is proactive: for example, comprehensive health care which is consistently supportive but also responsive when needs change. We need integrated data. Everybody is collecting their data here, there and everywhere, but I believe we really need a solid

database so that we can really engage in some thoughtful, strategic planning to ensure that both ends of the spectrum of needs are addressed. We need to be able to project needs of individuals as they're coming up through the system and develop responsive supports accordingly. We need to focus on prevention as well as responding to crisis situations. When you're always serving the pressures on the system, it has to come at the cost of serving more, but less severe, individuals. Finally, we really need a commitment of multi-year funding to enable the evolution of sustainable supports for our vulnerable citizens.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your comprehensive presentation this morning. We will have about three minutes for each party. Ms. Hunter, you may start.

Ms. Mitzie Hunter: Thank you, Madam Chair. Ms. Baldwin, thank you so much for just the details you've provided and the research to support your presentation. I do want to assure you that the recommendations you've provided are very consistent with the mandate of this committee. It is being well received.

A couple of questions that I have: You mentioned that a database is needed, and a comprehensive one, that could feed into the strategies. Do you see a role for the DSO in helping to coordinate that?

1000

Ms. Leanne Baldwin: I think they're beginning to have a good database. I guess it's just scratching the surface.

We have a very good executive director in our area, Gary Whetung. He has set up an advisory committee to his work. It's a difficult task and he has gone about it the best he can, following the guidelines.

Whether it's a DSO—obviously, they would have a good start on it—but I just feel that being part of a planning body for so long, it would be really great to be able to know the kind of diagnoses we're faced with across a lifespan. How can we plan and be very strategic—we're never going to have enough resources, so we need to come up with shared-care models. We need to come up with different kinds of models of service that are going to support our clients and our individuals that we're serving. However, if we don't know what's coming up through the school system into the next period of their life, then we have no way of being proactive.

We know, for example, that as individuals with developmental disabilities age, there tends to be more comorbid conditions. What are you going to do with that? If we know that there's X number of individuals who have, perhaps, Down syndrome—while it's not one-to-one correlation, many do go on to develop Alzheimer's; what does that mean for the system? What does that mean for health services? What does that mean for planning better supports before they're in crisis for those supports?

Could the DSO do it? I don't really know. I think it's early days. I think the DSO and the report that you've

been provided with is a good stab at some preliminary information. Does it take into consideration health care usage? No. There's a need to have information from the emergency visits, from the visits to psychiatry, from education. That's where I feel that we need to have some kind of integrated pool of information to say, "Let's get a handle on this. What are our priorities? How can we best address this going forward?"

Ms. Mitzie Hunter: That's excellent.

The Chair (Mrs. Laura Albanese): Thank you. Sorry; we have to move on to Ms. Jones.

Ms. Sylvia Jones: Thank you. There's a lot of excellent detail in here. The numbers concern me greatly. We all hear about waiting lists, but now we've got at-risk lists and we've got abandonment lists and we've got—what was the other one you said?—pressures lists. When does it stop?

You made reference, at the front of your presentation, to 363 people in Peel who would accept residential support if it was offered yesterday. You also talked about some innovation that's happening with parents who, quite frankly, have got tired of waiting. Can you share with the committee a few examples of those innovations, and more importantly, why they're getting blocked or where the block is happening?

Ms. Leanne Baldwin: I think that parents have come up with, I suppose, cost-sharing methods of pooling their resources together to come up with a day program, for example, or pooling their resources together to make a plan for taking over a house. I think the barriers that arise out of that is, you still need to operate it. You might have capital; you might have a place for people to live; but you may not have any money to staff that situation. So you need to partner with social services or you need to find somebody to partner with that's going to have some injection of ongoing funding to do the human resource support aspect of it. That's it in a nutshell.

In terms of the number of clients that are waiting, that was provided to me this week. The DSO doesn't track how many clients are on a waiting list that have been on a waiting list forever. One of their questions, I believe, is that, "If you were offered residential services or some residential supports tomorrow, would you take it?" It's kind of like the long-term-care situation, isn't it? You've got a bed in a nursing home: "Do you want it now or not?" Game over.

They have asked that question, and 364 people have said—or whatever it is, sorry. I'm not looking at my document.

Ms. Sylvia Jones: It's 363.

Ms. Leanne Baldwin: So 353—

Ms. Sylvia Jones: Sixty-three—363.

Ms. Leanne Baldwin: —363 have said, "Yes, I want it yesterday. I want it. I'll take it."

Ms. Sylvia Jones: Yes, although I have spoken to some of those—

Ms. Leanne Baldwin: Now, part of that, they may be saying they're taking it because they feel they have no choice, too.

Ms. Sylvia Jones: Right, so they feel like they're in a bit of a box—

Ms. Leanne Baldwin: Right.

Ms. Sylvia Jones: —because then I get the phone call, saying, “That’s not really what I want right now. I know that I will need it eventually, along the continuum.” But that I don’t want to say no.

Ms. Leanne Baldwin: But I sat on a residential services management committee as well, before the DSO ever got into play, and I believe we had over 700 names on the list. That was people trying to be—“I want to be on the list, because I know sooner or later I’m going to need it.” But nonetheless, that still is a prodigious number of people who are going to need something sometime.

Ms. Sylvia Jones: Right. Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Jones. I will move on to Ms. DiNovo.

Ms. Cheri DiNovo: Thank you very much for this presentation. It was wonderful and packed with detail and packed with figures, which I, in particular, love.

First of all, I have a question to research. I’m sure we’ve asked this before, but I’m not sure we’ve had an answer yet from the ministry or whomever. The numbers of abandonment cases: We really need to know that. If Peel region is able to produce that, surely the ministry, or somebody, can produce those figures. That really tells us the nature of the humanitarian crisis we’re dealing with here, which is absolutely what we think it is.

Your suggestions are excellent. We know that there are many jurisdictions in Europe and here that don’t have any waiting lists at all for their services for developmental disabilities. My question is, really, do you know of or have you researched a jurisdiction that you think really has the best answer for the crisis we’re facing here?

Ms. Leanne Baldwin: You know, I’ll be honest with you and say no, I haven’t, personally. I did go through a lot of the select committee presentations and did hear that there are models in England and there are models in Australia. But I’m not personally familiar with them enough to speak articulately or to—

Ms. Cheri DiNovo: No problem. You’ve done due diligence. You’ve done excellent work.

The other thing that jumped out at me, too, was the discrepancy in per capita funding, which clearly is unfair. If some regions are getting more per capita funding than others, then that’s something that we really need to look at. So I just want to thank you for that.

Ms. Leanne Baldwin: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very—

Ms. Leanne Baldwin: Sorry. I believe the Fair Share for Peel process has been around for about 20 years as well, and I’ve participated in that for a very long time as well. I think that speaks to the age of me. They, too, have well-documented figures.

I do want to say that the central west region of the Ministry of Community and Social Services has always

been extremely great to work with and very willing to help us try to address areas and be creative and come up with different kinds of solutions. We’re just facing a wall.

The Chair (Mrs. Laura Albanese): Thank you very much. We’ve reached our time limit.

Ms. Leanne Baldwin: Okay. Well, thank you very much.

The Chair (Mrs. Laura Albanese): Thank you for presenting to the committee and bringing forward all of this information. It’s very useful.

RYGIEL SUPPORTS FOR COMMUNITY LIVING

The Chair (Mrs. Laura Albanese): Our next presenter is—I don’t know if I’m pronouncing this right—Rygiel Supports for Community Living. I will ask you to come forward. We welcome the executive director, Donna Marcaccio. Please make yourself comfortable. You will have up to 20 minutes for your presentation. If it’s any shorter, then we’ll divide the time equally for questions.

Ms. Donna Marcaccio: Thank you very much. My presentation is short, and it’s somewhat informal. I’m well aware that the committee has received numerous presentations with lots of facts. Mine is a little bit different.

Just to further introduce myself, I am the executive director of Rygiel Supports for Community Living in Hamilton. We have been providing service in our community—we’re in our 46th year—particularly focusing on the individuals with the most significant cognitive disability and multiple physical handicaps.

Many of these young people—well, they’re not so young now. Many of these people were abandoned in their childhood, and others along the way. Of the 180 people we support, about half of them do not have any family—any significant relationship that you and I would consider important in our lives.

So my message today—the handout really is just a summary of my two key points.

1010

Our agency’s history is that we were a schedule 2 facility, so in the province of Ontario we had our government-operated facilities. We were one of the first community transfer payment institutions and we were the first to self-deinstitutionalize throughout the early 1970s up until 1980. That was all driven by the principles of normalization. We take great pride in having those principles that lie in that philosophical and social structure as the roots of our organization, which have driven us over the years.

It is those principles that helped us be one of the first agencies to pilot respite care and shared care in Ontario. As we all know, respite has become a very popular service structure and a least-intrusive service structure, and, for a family, one of the most critical supports we can offer to them. As a service provider as well as—I’ll

declare I'm also a family member not using service. In both roles I'm well aware that as a province we've been able to provide more and more respite, but one of the key messages I bring to you today is that services such as respite have become so regimented that it undermines the intention of what respite is.

As an organization we, like all others, have striven to do the best we can and to live according to our mandate and mission. When it comes to resources—and we're grateful for the ongoing recognition of our province of the service needs and providing more and more resources—the reality is, what comes from the province is only a fraction of what it truly costs to support a person with a basic lifestyle.

One of my concerns whenever we talk about developmental services is that we only look to the province and to our government and we don't talk about our community. We don't talk about what it really costs and how our communities have contributed significantly. Just as an example, in our organization it has been wonderful that we've received operational dollars to care for people, but we're serving a population who can't go and rent a house or an apartment. They need barrier-free design. Yes, there are lots of non-profit, barrier-free townhouses; only two people can live there, but if you have an extended wheelchair, maybe only one can fit. We have lots of those.

We have created, over the last many years, our own non-profit housing corporation, and it's through the goodwill of our community, lots of volunteers and wise financial management that we've been able to provide 15 completely accessible houses to our community and to continue with that commitment of providing more. That needs to be recognized. We're one of many, many organizations and many communities where it's a partnership between the community and our government. I think that needs to be talked about more as we face this crisis.

Just a couple of operational challenges that really impact our ability to be more flexible and responsive—again, I'm not going into a lot of detail because I know you've heard about this. For example, as an organization where we're having to respond to conflicting legislation. For example, pay equity is a very serious issue. In our organization alone we are faced with not reaching pay equity until at least 2021. By the time we're finished, it will have used the resources equivalent to 66 full-time employees. That affects a significant number of people with disabilities. The conflict in meeting that legislation is that we're in conflict with our own legislation, which says, and rightly so, "You cannot affect the service targets that you provide."

Fire code: I'm sure you've heard about that. That is another conflicting—we have a philosophical issue where we're turning houses into institutions. We have legislation that's not clear for our sector. The legislation says that if the occupancy is more than 10 residents and more than three storeys—this is a requirement. We provide bungalow care for three to four to five people, and no one knows where we fit. We're having to spend an

enormous amount of money to retrofit to a standard, and nobody is really clear what that standard should be. In the midst of that, where we have capacity to welcome one or two more people into a house, we're not allowed to do that because we can't change occupancy until the fire code issue gets resolved. So we have spent an enormous amount of hours—not alone—and these conflicts really affect our ability and your ability to respond to our vulnerable citizens.

Then, of course, the whole issue of mandatory requirements on agencies and just a small example of that: Understandably, our ministry, several years ago, mandated all residential services to train their staff within 30 days of employment in non-violent crisis intervention or some form of restraint training. In an organization like ours, we have always had a no-restraint policy from a philosophical and research perspective, where it's clearly research that restraining somebody only adds to the agitation. We have a no-restraint policy, and more importantly, 90% of the people we support can't move their own limbs. But every year, we have to spend an inordinate amount of money, at least \$25,000 and up, to train people in something that they will not use within our organization.

Equally as important, having to do that is bringing back into our culture in our province the ancient stereotypes that we've spent decades trying to eradicate: that anybody with a disability is going to be violent, is going to be aggressive etc. There are people; it's a small population. I ask: Why isn't it mandated that I have to teach everybody sign language or alternatives to communication within their first 30 days of employment? I have to teach them something that suggests that the people on the other side of the door may harm you. So I bring that forward and ask the committee to seriously look at some of these issues that put organizations and families—more so, the people we're here to serve—in this very difficult situation where, while there was good intention on one part, quick and blanket decisions are actually causing a lot of difficulties.

My second key point is actually responding to some of the issues of the previous speaker, and that is for families. While it's very understandable why the structure of DSO came into existence and how helpful it is in many ways, it also becomes a challenge because it has created a very, very highly structured service system, again, with a degree of understanding. However, I bring forward and ask you to consider: Is there a way for us to bring back some of the grassroots flexibility in our system?

Developmental services, like many other non-profit sectors, started with families coming together, helping one another, and community members helping them. That's the root of our agency and it's the root of many. Families today do want to be playful—many families. Many families do put resources aside for the future, but clearly a lifetime of resourcing is not anything that any family—there may be a couple of families, but most families—would ever be able to achieve. So families coming together and planning and sharing resources have

great limitations, yet we say we want families to do more. But we have no mechanism to support that. Respite is a little bit of a mechanism, but again, highly structured programs that we've put in place sometimes undermine that. Families need responsive respite. They need it with more flexibility. Yes, they need some predictability, but if something comes up in a family—a family member dies—they need some care while they deal with that. How do you get that quickly? You don't anymore.

Families who are planning for the lifetime future of their family member used to be able to partner with agencies. They used to be able to come together and say, "Today I only need a respite, a weekend a month, but down the road I'm going to need this." And you worked and planned together and you knew each other and you knew the family member and there was security: emotional security, knowledge security, etc. All that is gone. A family for whom we provide respite now says, "I have these ideas. I'd really like you to work with us and develop them. Where do you think I might be able to get some resources in five years?" That's what my budget tells me.

1020

I legitimately, as agency staff, can't be helping them, because they're not referred to us through the DSO, and our resources have to go to people referred to us through DSO. I'd gladly do it as a volunteer, but I have no answers for them.

We need to build in some way of helping families who are willing to do things and plan for their family member, but if two or three families come together and they look at being able to sustain some kind of support, whether it's respite, day supports, accommodations down the road, the reality is that the day will come when they need some help from the system. Who is to say that they will be at the top of the list—all three, or all two? The chances are very slim. So those families become broken; the arrangement they've made has become broken.

My real message today is that we need to look at how we back up families. We'd have families who received respite who would say, "If my son or daughter is in their day program and they get sick, can you be a backup if I can't get away from work?", and we would do that. Do you know how often we got called upon? Almost nil. The security that that gave families was beyond what we could put dollars to.

We can't do those kinds of flexible services and supports to families anymore. We need to find a way, because we can't afford to provide—nor should we—very intrusive service to people. We need to provide what they need, and a lot of people only need minimal support and backup. They need to know someone is there if there's going to be a crisis. They need to know they can be planned for, and that they've got somebody and some organization behind them for that planning.

We've created a very comprehensive service system, but it's quite fragmented. It has become very structured. We have wonderful legislation that talks about people being members of their community—a person-centred,

person-directed service system—but the actual fact is that it's very fragmented and structured, and it's taking away from people really being part of family and community.

So I encourage this process to consider ways of building flexibility into the structures and funding models, as well as regulations that will help families build a more normative lifestyle with adequate supports for their family member, a lifestyle that's rooted in community, not in agency; a lifestyle that's rooted in meaningful relationships. There's a role for agencies to provide this flexible soft service, to partner with families, and I suggest that this will really be a significant contribution to the transformation agenda.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation. That brings forward points that are a bit different and highlights different aspects of the issue.

We have about two minutes per party, so we'll begin with Ms. Elliott.

Mrs. Christine Elliott: Ms. Marcaccio, thank you very much for your very thoughtful presentation. You have certainly raised a number of the issues that we have heard about, but you have some innovative solutions, by the sounds of things.

I wanted to ask you: I took a note that you had created a non-profit housing corporation that was working with the community and with government. Could you provide us with a few more details of how that was set up, please?

Ms. Donna Marcaccio: Basically, we learned from other non-profit groups. We incorporated a group of volunteers to become a founding body and registered it. Basically, it took some volunteer dollars, donated dollars, bought a house and used that as equity and continued to build on that equity. The individuals rent from that corporation.

Mrs. Christine Elliott: So you were able to do that through private donations, basically.

Ms. Donna Marcaccio: Yes.

Mrs. Christine Elliott: And you were able to actually purchase the residences.

Ms. Donna Marcaccio: The original houses, and then the individuals pay rent to pay off the mortgage now.

Mrs. Christine Elliott: Okay. Do you think that's something that we could replicate across the province?

Ms. Donna Marcaccio: There are many good examples of it throughout the province. Some call it a foundation, some not. There are quite a few examples in our sector. It's not well understood. It's a model that really works and builds equity for our system, as well as providing immediate appropriate housing.

Mrs. Christine Elliott: That's great. I think it's happening—

Ms. Donna Marcaccio: I'm happy to share whatever—

Mrs. Christine Elliott: That would be helpful. I believe it's happening in Peterborough as well, with their Community Living, and it may be happening elsewhere.

We're just not that familiar with it. But if you could provide us with more information, that would be great.

Ms. Donna Marcaccio: I will do so.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Thank you, Ms. Elliott. Miss Taylor.

Miss Monique Taylor: Thank you so much. Thanks, Donna, for being here today. We've met several times; we've had many conversations. I know the great work that you do in this sector and the hard times that you find this sector falling through.

I would hope that you could share with the committee some of the problems that you find within your facilities for the lack of funds, and the troubles that that's putting you in, and what's happening to our resources because of that lack of funds.

Ms. Donna Marcaccio: I could spend a day, so I'll just pick a couple of examples. In order to meet our pay equity legislation, we actually had to sell a house. Fortunately, we were able to put more people into a house and relocate, just prior to all the hype around the fire code. If we wanted to do that today, we wouldn't be able to do that, because we can't change occupancy.

There's a fine line, and there is a lot of research out there—we're doing it, as an agency—of what the impact is on groupings.

We've had a very interesting experience as a result of recent financial pressures. We added capacity, so we went from a four-person to a five-person residence. One of the individuals who originally lived there had a history of some very traumatic times in her life, emotionally. Her last 10 years have been amazing. She goes to the gym. She does all kinds of things with her support and with volunteers, and she actually has some real friends now.

It just came to my attention within the last few weeks that as a result of the increased number in the house—therefore, greater chaos, and so on and so forth—some of what was exhibited prior to 10 years ago is starting to happen again, which means she now needs to be referred to the behaviour management team in our community, and we need to do other training for our staff, and so on and so forth. Her home—a place of security and a place where you're supposed to be comfortable and trusting and be able to be yourself—is changing.

It is a balance. I understand that our group homes, our residences, are part of the system and not home like my home, but we have to find a balance. We had a balance in that home, and we don't now.

Resources, on the one hand—because of increased costs and no change to resources coming in, we've had to take some measures to meet all these obligations. The impact on the individuals isn't always for the best, and in the end, it's not cost savings, because now there are other costs being incurred to the system.

For time, I'll just leave that as an example. I'm happy to answer and provide more, if you'd like.

Miss Monique Taylor: Thanks, Donna.

The Chair (Mrs. Laura Albanese): It's a good example. Ms. Hunter?

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you so much for your presentation and the work that you and your organization are doing for people with developmental disabilities.

I was very interested in your support to families. We've heard a lot about that in terms of families really wanting to provide that natural support, but they need to be backed up. Can you talk a little bit more about what you see families are most in need of, in terms of getting that backup support so that they can provide the natural supports?

Ms. Donna Marcaccio: What I hear over and over again, and I can personally appreciate, is the importance for some spontaneity. I use that example of, let's say there's a family of four: a person with a disability, a sibling, Mom and Dad, and one of the parents gets very ill. They haven't got any respite dollars other than maybe a weekend every seven or eight weeks. What do they do? They don't have extended family; they don't have any support. There needs to be some flexibility. The system has become so rigid that that flexibility—it's a crisis, and somewhere, somehow, we always seem to manage a crisis, but is that in the best interest of that family?

When that happens, it might be the agency that's providing the ongoing respite, but because it's a crisis, it may have to be somebody completely new. That does not give families a lot of security. They live in anxiety: "Who will know my family member? How will they adjust to a foreign environment and different people in a crisis?" It's already traumatic, having to be removed from your home, or bringing somebody new into your home.

1030

The other thing is that, as the world becomes more refined, or fragmented, as I call it, as well as tight rules—regimented—families are overwhelmed with the responsibility that comes from hiring workers, paying workers, considering WSIB, and all those issues. That administrative piece needs to be simplified. As an agency, we do a lot of that for families. How much longer can we do it without any resources to cover that? I don't know. We use a lot of donated funds to help offset that. Communities are amazing, but it's getting to a point where that's really becoming very difficult for an agency like ours. We raise money to buy houses, and we raise money for vehicles and then daily supports, so it's very challenging.

For families, it's the backup of, "I need to go somewhere today with my other sibling. Can I bring my child to the residence where they have respite, because they're their friends, just for an hour or two?" I used to be able to do that. Now I have to say no, because it's not part of their approved service.

The Chair (Mrs. Laura Albanese): Thank you. Unfortunately, the time has expired. But at the same time, we want to thank you for your thoughtful presentation to our committee. We'll take those considerations.

Ms. Donna Marcaccio: Thank you for having me.

HALTON SPECIAL NEEDS
FAMILY NETWORK

The Chair (Mrs. Laura Albanese): We now welcome Halton Special Needs Family Network. Good morning.

Mr. Nick Norvack: Good morning.

Mr. Tom Mahoney: Good morning.

The Chair (Mrs. Laura Albanese): I saw that you were sitting in the audience for a while, so I think you know more or less the way the committee works: up to 20 minutes for the presentation. If any time is left over, we'll ask questions. You may begin any time. If you could begin, please, by stating your name and title.

Mr. Nick Norvack: Okay. First of all, my name is Nick Norvack. We wish to thank the committee for allowing us this opportunity to raise our concerns with regard to the present difficulties facing those who are developmentally disabled.

Rather than read directly from our written submission, I will provide you with my experience as a father to a 24-year-old daughter who is developmentally disabled, and as a member of the board of directors for Community Living Oakville.

My daughter Samantha is presently attending a fee-for-service program provided by CLO called STEPP, Skills Training to Enable Personal Progress. The program costs \$40 a day, approximately \$12,000 a year. At the time of her completion of her life skills program from high school, we were placed on the Passport funding wait-list, and to this day we have incurred the majority of the costs of her STEPP program.

In order to ensure the maintenance and success of the program, I became a member of CLO's board of directors. My initial observation was of a considerable amount of funding provided by MCSS for residential homes—approximately \$6 million a year, for 75 individuals; average cost, \$80,000—and the total lack of funding for other programs and individuals.

Although 48 adults between the ages of 21 and 26, who presently live with their parents, are presently enrolled in the STEPP program, the program receives absolutely no funding from the ministry. Since the entire costs are borne by the parents, many of whom have limited or no funding, many of the participants can only attend part-time.

Our Best Pack and Speers Place Industries programs, which provide employment and learning skills opportunities for 80 individuals, also receive minimal funding from the ministry. Last year, eight of these individuals were provided with sufficient skills to actually find full-time employment in the community. Unfortunately, the annual shortfall between expenses and income from these enterprises is borne solely by CLO, even though these enterprises provide a positive experience for the individual and community.

However, the most revealing aspect regarding ministry funding is our latest residential home. After CLO purchased the home for five complex-needs young adults,

for \$630,000, the ministry provided us with \$150,000 for renovations and \$75,000 for furnishings. Noting the complex needs of these individuals, the ministry provided us with an annual operating budget of \$950,000 for staffing.

Assuming an annual 2% cost of living over the next 40 years, since these kids are only in their early 20s, the total operating expense will be \$59.2 million. Considering the ministry has informed us that the numerous complex-needs individuals still without homes will be serviced next, this residential home model is almost financially unsustainable for the province.

With regard to DSO and the comments presented to the committee by previous presenters over the length of testing, my concern is more directed to the impact that the scores arrived at from the supports intensity scale testing has on the parents. For instance, my daughter scored at the 86th percentile level, which should correspond to the highest level of Passport funding. However, we were only provided with \$2,700, which was the direct transfer amount from her previous SSAH funding, an amount which would not have been available now if she was just turning 18.

In addition, the committee may find it interesting that the American test used actually refers throughout its paper to the 1,500 individuals used in devising the test as "MRs." In addition, the percentage of these individuals who were categorized as autistic was 0.4%; that is, six out of the 1,500 were autistic. There is no way this is a fair representation of those presently taking the test in Ontario, and I would question the validity of any of its findings for these autistic individuals.

I'll pass it over to Tom now.

Mr. Tom Mahoney: Good morning. My name is Tom Mahoney and I'm here with Nick representing the Halton Special Needs Family Network. I'm a single parent. I have three children. My youngest son, Connor, is an autistic 22-year-old who also suffers from seizures.

My comments today are a cumulative reflection of my own and our Halton special needs families' experiences.

I'm going to stray from my context that I've handed you before because I'd like to speak directly to you. You have heard many, many horror stories—the continuity of statistics by region within this province. I'd just like to start right at the very top, or at the very beginning of what life is like as a special needs family.

First of all, we have a diagnosis made. Today, if you're lucky enough that it can be defined that you are eligible for intensive behaviour supports, you will get them. If you're not, you are left on your own on a waiting list. You then must go and find supports for your child to help them with the modelling of behaviour. I want to keep this thought in mind of behaviour modelling throughout this presentation, because that is the overall goal throughout this whole process. By the time our children reach the age of being graduated out of high school, it's the behavioural model that must be reinforced, and hopefully all the resources that we have put into that behavioural

model will pay off. If it doesn't, we have thrown away hundreds of thousands of dollars per individual.

During grade school, your child goes into a fully integrated process in the middle and amongst all their age peers and age brackets. They have a wonderful time. They're totally integrated within the community. That continues until they reach high school. In high school—never forgetting, there's an IEP done for every year for each individual. By law, that IEP must be signed. I want you to know that the IEP is this thick. Parents have a terribly difficult time of understanding, "What am I trying to achieve with this IEP? Is it academic or is it behavioural?" What are the points of measurement within that IEP? There are none. Teachers don't have any tools to measure progress through that process.

Let's get to high school. We now put them into programs where they have a central location for special needs, and hopefully they have the behavioural skills at that time to move through the high school. Many times, they don't. When we had the dream of inclusion, we've just pulled back on that inclusion. They move through the school with best programming—once again, it's the IEP process. Do those IEPs support the behavioural modifications that we need? The whole objective in everything that we do is to remove the ideal of a five-to-one ratio at particular times where I need five people to look after my special needs child down to four, down to three, down to two, down to one, and then moving it on the opposite side. They can now be part of a group of five kids to one attendant or 10 individuals to one attendant, and keep moving them in that process. That is our objective.

1040

After high school, they are graduated out at 21. We have no idea how well they are performing from a functional standpoint, but then they move into the realm of Passport. Before I get to that, the Special Services at Home, hopefully, at one time were supporting them throughout this process. The history of Special Services at Home was that they got an immediate amount—I'll give my own history—of \$3,000 a year. That amount was the same until my son reached 19, so from six years old till 19. When he transferred over to Passport, it was still the same amount, and still is the same amount today. This is the only sector within government services that has been based on a zero-based financial model, and that goes completely down to the supports that are given to Community Living, to Christian Horizons. We also ask them to pick up, learn from within, take from within. We'll make changes with fire codes and we'll make changes here, but we will always have to work on a zero-based budget. I work with a zero-based budget of supports.

I'll never forget within school, again—pardon me for moving around a little bit—but school and education for families is 35 weeks a year. What happens with the other 17? My Special Services at Home supports were totally allocated to programming for the summer time, and hopefully I could structure that programming to support

the learning and the IEP process that I had within the educational system so that I have continuity.

Once again, with the Passport Program, we move forward to the process of having to qualify. There's no use even asking for support unless I have an IQ below 70. This is ridiculous. Many special needs have an IQ over 70, but they don't have the behaviour adaptations that correlate to that IQ. Their behaviours are of five-year-olds, but we accept that; that's fine.

I'd like to immediately jump right now into establishing recommendations. I went a little longer than I had intended initially and I apologize for that, so I'll quickly try and read these, and hopefully we can have a little bit of discussion about them.

(1) First of all, yes please, establish a single lead agency contact point for all clients and family contact.

(2) Immediately provide bridge supports to all families on waiting lists, allowing for program access. The longer you wait, the more costly it will become. This will allow for service providers to guarantee available programming, which is now at great risk. Please don't throw that money away that has been spent on them throughout their whole education process, by allowing them to sit at home and re-learning all the bad behaviours that they knew previously.

(3) Support funding should be administered using the direct funding method to the family. In many circumstances, even with approval for funding, the families are unable to secure appropriate day services because of their location or lack of services being offered.

(4) Bridge residential supports to families until long-term solutions can be implemented. We also recommend that consideration be given to new non-profit strategies, and there's one I'd like—if you have questions about it, it's the Habitat for Humanity business model. Here, homes are owned by the clients, the special needs themselves. The way it works is that Habitat for Humanity will own the mortgage. It is interest-free. The client then pays back that mortgage over a 30-year time period. It is recognized that there will not be a single solution but a number of best solutions that embrace the unique individuality and personality of each person. Please never forget that the housing—the home—is an individual's choice. We got rid of the institutional model because of the inhumanity of it. An institutional model, even with five people in the home, can be exactly the same thing to the individual.

(5) Initiate a "perfect 10" work strategy, where 10% of all provincial government employees are individuals with special needs. The problem we have with ministries is that they have become more financially challenged on the basis of where does the money go, versus goal-oriented. If we achieve our start point, a goal of jobs for all, then all the behaviours and all the movements that we have from starting in primary school will lead up to that point. We want them prepared to be able to go to work. That's our objective. Their ability to work really, truly is the meaning of being included equally within our society. As it stands right now, every individual who is residing at

home will not have that opportunity. The “perfect 10” sets the goal of 10% higher for people with special needs within the public sector, and this is to be achieved by the year 2020. As an example, the US Senate’s subcommittee has a recommendation that there are going to be 600,000 special-needs employees within the federal public service by 2017. They have taken on this challenge, and they have set that goal.

(6) A championing of special needs in the private sector: that an Ontario Chamber of Commerce partnership be initiated, providing examples of the amazing corporate experiences for those companies that have initiated a 10% to 20% special-needs hiring mandate. There are examples of this through Walgreens in the United States, which at every fulfillment centre has a mandate of 20% higher for special needs. They also take these individuals in and train them themselves. The actual cost to Walgreens per employee in additional training costs is \$400. Their experience has been phenomenal. They have moved it down now to the next level, where they are looking at every grocery store now having a minimum of 10% special-needs hiring. Individual companies working with Walgreens—Procter and Gamble fulfillment centres—have also set that 20% goal.

(7) Initiate a special-needs public transit strategy which mandates that all ODSP recipients receive 50% transit discounts, and that any attendant who travels with them is not charged for any transit authority that is supported by the province of Ontario. The city of Toronto just announced that attendants will not be charged—I believe a month ago. Previous to that, special needs were penalized. If I had to be at a doctor’s appointment and I had to take the TTC and my attendant had to go with me, I have to pay two fees. If a person with a seeing-eye dog gets on for free, it’s not equitably fair. The other part is that, given that ODSP is their major income source, a Metropass or any regional pass right now is in the neighbourhood of \$200 a month. How do they get to and from work when 25% of their monthly budget allowance without income is utilized just in transportation?

In closing, one Saturday morning I opened up the Hamilton Spectator. On the front page were three individuals in their 60s. They live on ODSP, and they’re living in absolute squalor. The toilet is frozen. One woman living there killed a rat the night before with a toaster. I looked at that picture, and what I saw coming back to me was my son.

With the systems that we have in place now, we lose these individuals as time progresses. This, ladies and gentlemen, is no longer acceptable. The challenge to you as a panel is probably the most important challenge you will ever have in your lives. I ask you to bring party consistencies and objectives all focused forward to support these marginalized individuals.

We live in the greatest province in the world, but as long as we marginalize these individuals, we’re fooling ourselves; we’re not. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much. We just have time for a comment for about a

minute. We could use it for a quick question or a comment, and it would be the NDP’s turn to start.

Ms. Cheri DiNovo: Thank you very much for this presentation. Of course, we’ve heard similar themes throughout our days of hearings on this issue, so you’re not alone. I want to tell you that, first of all, and say that we are all here charged with exactly what you have just charged us with: that we do something, that we recommend something, that we make change. That’s what we’re all here to do.

I particularly liked your idea of the public service setting targets for those with special needs in terms of hires. I thought that was excellent. I think that’s the first time I’ve heard that, so that definitely goes into the roster. Thank you very much.

The Chair (Mrs. Laura Albanese): Mr. Balkissoon?

Mr. Bas Balkissoon: Thank you, Madam Chair. Let me say thank you for being here and sharing your thoughts with us. Just to echo the same thoughts of my colleague, the committee was struck so that we could go out and get this kind of data, so that we would make recommendations to the government. I can assure you we’re working as a team here.

1050

Based on previous experience of doing similar work in mental health, hopefully, the report that will come out will be very positive, and it’s up to the government to implement it.

But thank you very much for taking the time.

Mr. Tom Mahoney: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Elliott.

Mrs. Christine Elliott: I also would like to thank you very much for your presentation and, again, to assure you that we are working together here—we want to set up a framework that can be followed by anyone—and that we are going to see this through. This is not something that we’re just sitting around here listening to people and then we’ll write a report and nothing will come of it. We’re all personally committed to making sure that change happens. I hope that you feel assured by that.

I just wanted to make one comment. I’m also very strongly in favour of having a champion in the private sector to bring employment and opportunities for young people. You may be aware of the Rotary at Work initiative. I think they’re doing some really groundbreaking work. Some of the private sector employers have made it their business to hire people with special needs, not as an act of charity but as a good business practice. As you’ve indicated with the Walgreens example, it’s very little that needs to be done by the employer, and the benefits that come back are huge. So thank you very much for bringing that forward.

Mr. Tom Mahoney: Thank you.

The Chair (Mrs. Laura Albanese): I, too, want to thank you again for your presentation and assure you that we’re trying to work in a very non-partisan way. We’re looking at issues, at the needs, that we’re hearing, and we hope to put together a good, comprehensive report that

will bring some results to the people who need it: the most vulnerable. Thank you very much.

Mr. Tom Mahoney: Thank you.

FAMILY SERVICE TORONTO

The Chair (Mrs. Laura Albanese): We'll now welcome Family Service Toronto. Good morning.

Ms. Janet McCrimmon: Good morning.

The Chair (Mrs. Laura Albanese): Please make yourself comfortable.

Ms. Janet McCrimmon: Thank you.

The Chair (Mrs. Laura Albanese): If you could kindly introduce yourselves before you start. You'll have up to 20 minutes for your presentation.

Ms. Janet McCrimmon: Good morning. My name is Janet McCrimmon, and I work at Family Service Toronto as the director of Building Inclusive Communities, which is the part of our organization that serves children and adults with developmental disabilities. I'm here with a couple of our staff and with a parent of one of the clients in our program. We really appreciate this opportunity to talk to you about some of the challenges that people with developmental disabilities are facing in our communities.

FST is a proud United Way agency. We've been serving individuals in Toronto for 100 years this year. It's our anniversary, and we're very proud of that. We provide counselling, community development, public education and advocacy. We have 13 locations in Toronto, and we served 65,000 people last year in 20 different languages.

We provide several programs that partner with individuals with developmental disabilities, and their families, to promote inclusion and improve the quality of their lives. Our Options program supports more than 450 children and adults with developmental disabilities, and their families, to achieve their potential through person-directed planning, service coordination, individualized funding, circles of support, supportive counselling, self-advocacy and mutual support groups. We connect people to opportunities for employment, inclusive education, recreation, living arrangements and opportunities to develop new relationships in the community.

FST also administers the MCSS-funded Passport Program in Toronto, providing individualized funding to more than 2,500 adults with developmental disabilities to access community participation supports and to enable respite for caregivers.

We are the lead agency for person-directed planning in Toronto, partnering with seven other developmental service organizations to deliver this important service and build system capacity for person-directed planning.

We also have a dedicated counsellor in our Violence Against Women program who works with women with developmental disabilities who have experienced abuse.

Our 23 years of experience in delivering these programs, and in listening to the individuals we support, form the basis for our presentation today.

The key messages we want to convey are:

(1) Individualized funding that's flexible and can change as individuals' needs change is a critical part of the developmental service system. Such funding has the potential to transform people's lives, and we encourage the government to expand its support of this approach to service.

(2) The current level of support for our community members with developmental disabilities is inadequate, and lengthy waiting lists for individualized funding and services are creating crisis situations for many.

(3) Individuals who are experiencing life transitions—for example, young people transitioning into adulthood and individuals who are aging—are particularly at risk of destabilization and crisis due to the interruptions of service and funding that they experience. We need better strategies that will enable a continuum of support and service for these individuals and their families.

(4) The lack of affordable and supportive housing options for individuals with developmental disabilities is a significant barrier to improving the quality of people's lives.

To help elaborate on some of these points, we've invited Patricia Parker to share her experiences with you as the parent of Victoria, an individual receiving service through our Options program.

Ms. Patricia Parker: Good morning. I'm Patricia Parker and I am here presenting to the Select Committee on Developmental Services this morning as a parent.

My 41-year-old daughter Victoria has Prader-Willi syndrome. We're really grateful to have been receiving individualized funding, since 1998 actually, from the Options program of the Ministry of Community and Social Services. The flexible and family-focused nature of this kind of funding has made it possible for Victoria to live independently, safely and with a high quality of life in her own apartment in the community of her choice, the neighbourhood of her choice, for the past 16 years.

What works so powerfully for us is that with individualized support, Victoria and her family are the true authors of her support model. Options capitalizes on the knowledge and strengths of Victoria, her family, her support workers and others who are part of her caring community. Victoria's supporters are resourceful, experienced and talented. In a more conventional funding environment, where we would only be consulted at an annual review meeting, our contribution would be lost and Victoria's needs would not be as well served as they are.

My understanding of the individualized funding program of Options, from its inception in 1998 as a pilot initiative of MCSS, is that the ministry wanted to develop an innovative and participatory model of individualized funding. Our family's partnership with Options has created, at a relatively low cost, a safe, secure and meaningful life for Victoria that is almost miraculous. All the medical, behavioural and research literature about Prader-Willi syndrome emphasizes that those affected cannot live safely without around-the-clock supervision.

And yet, together, as partners, we have successfully supported Victoria in defying those odds.

For MCSS, Victoria's life, I believe, is the best possible illustration of the effectiveness of individualized funding and also the power of partnerships with families. This collaboration has been life-altering for our whole family and, I actually believe, life-saving for Victoria.

While our experience over the past 16 years has been rewarding and gratifying, there are two concerns that I do want to speak about this morning. Actually, there are a whole lot more concerns, but I'll speak about two.

First, our family's success story with individualized funding is far too rare. The more common reality is that many of our most vulnerable citizens are not adequately supported, are often in medical, psychiatric and behavioural crisis, and, in fact, are at high risk of dying prematurely as well as unnecessarily.

While the Options model is innovative and successful, it's very limited in scope with respect to individualized funding, and there is currently no expectation that the ministry will allocate more funding to it. This means that other families who would so clearly benefit from inclusion in this program have no realistic hope of gaining access to it.

This is relevant to my second equally significant concern. Many people with developmental and mental health challenges are living longer than ever before, and there is no provision within Options for responding to the changing needs of its aging participants or to compensate for the increasing frailty and ultimate mortality of the parents and other family members who have been crucial to the program's success so far.

The MCSS's Options partnership with families has been a successful collaborative model for over 16 years. Now we're at the point where we have both the opportunity and the responsibility to be innovative in our approach to the next stage of planning. It's time to think differently about the delivery of developmental programs and services, and also to think differently about the role of government ministries, families, communities, corporations and the non-profit sector. I used to think that there was a crisis looming in the developmental and mental health services sector. In fact, we are in full-fledged crisis right now.

1100

When elderly parents are afraid of dying, when they say, "I just need to live one day longer than my son or daughter," there is something really wrong going on here. I can't tell you how many times I've heard that articulated. I can't tell you how many times I've thought that at 3 o'clock in the morning when I wasn't sleeping.

I'd like to make two specific recommendations to the select committee: first, that MCSS reaffirm its commitment to the model it implemented in 1998, so that individualized funding actually becomes a core component of our provincial funding strategy for developmental services, not a one-time closed shop; second, that there be a commitment across government ministries to be proactive, innovative and visionary with respect to the

changing needs of the aging population of our most vulnerable citizens. We must find ways of moving away from being crisis-driven.

I would like to have been able to tell you in more detail why the Options partnership works so well, particularly for Victoria, but also how our family is addressing the question, "What happens to the partnership necessary for individualized funding when the parents are no longer involved?"

Our family, and many families that I know, are not passive recipients of government assistance, nor do they want to be. They want to be full partners in moving ahead and planning for the future.

I have prepared some additional comments in the handout that I've given you for your consideration, with the hope that these thoughts also could be incorporated into your submission.

Thank you for giving me the opportunity to share some of our family's personal experiences and successes and for your consideration of my recommendations. Thank you.

Ms. Janet McCrimmon: Thank you, Patricia. The story that Patricia shared is one of many that demonstrates the tremendous difference that individualized funding programs, such as Options and Passport, can make. Such funding can promote choice, inclusion and independence—the independence that individuals seek and that the government envisioned in its SIPDDA legislation.

In expanding individualized funding, we urge the government to ensure that funding is as flexible as possible and is linked to person-directed supports that encourage individuals to plan for and build meaningful lives in their communities, building on their strengths and interests.

Our Options program, an individualized funding pilot program funded by MCSS in 1997, continues to provide 89 individuals with supports to develop visions for their lives and plans to realize those visions. Individualized funding removes barriers to these individuals achieving their potential and being active, valued, contributing members of their communities. Each individual's plan and budget is unique and can include different types of supportive housing arrangements, community activities, educational courses, support for volunteering, respite, therapies etc. This is a broader array of activities, services and supports than is currently available through the Passport Program.

In addition, the individualized funding system needs to be able to accommodate changing needs that individuals and families experience without long delays. An individual's funding level should be able to go up and down based on their priorities and their needs, as well as other services and supports received. It should also be possible to reallocate unused individualized funding to people who are waiting for funding in a timely fashion.

Unfortunately, the demand for individualized funding is far greater than available resources. Ministry data shows that there are more than 5,000 adults with developmental disabilities waiting for Passport, and there are 3,500

people who are in receipt of Passport funding but have asked for more because their needs have changed or the amount isn't meeting their needs. There hasn't been, as Patricia said, an increase in the amount of individualized funding available through Options for years.

I know you've heard a lot about waiting, and I don't want to talk too much about it, but you know that people are waiting for 18 months just to get an assessment at Developmental Services Ontario to determine whether they're eligible, and then they're put on waiting lists for service or for funding.

We hear regularly from people whose personal situations are heartbreaking, who have been waiting years for services or funding with no end to their wait in sight. We can't help but think that addressing their needs more proactively could have avoided some of these crisis situations. Historically, individuals have been able to access supports while they waited for funding or service from lead agencies; however, this level of support is not possible through the DSO, which is problematic.

Individuals experiencing life transitions are particularly impacted by systemic issues. Young adults who have benefited from participation in school, who have received Special Services at Home funding and other services, often suddenly find themselves isolated at home upon the completion of secondary school. These individuals must apply for an assessment with the DSO and then wait for funding or services. They are encouraged to apply for the ODSP benefit, but this doesn't provide sufficient income to meet basic needs, much less provide for community participation. This situation is incredibly destabilizing for individuals and families and has many ripple effects for the quality of life of these individuals, including negatively impacting caregivers' ability to engage in paid employment. Ensuring continuity of services and supports for young people as they become adults has to be a priority and would go a long way to preventing some of the crises that are currently occurring.

Patricia spoke about parents who are aging and individuals who are aging. There is a DSO council paper called *The Crisis of Aging with a Developmental Disability in Toronto*. We really encourage you to look at that document. Their recommendations are very good and a couple in particular that we're wanting you to look at are the idea of developing a cross-ministerial strategy for addressing the money issues associated with aging with developmental disabilities, and enabling age-adjusted funding.

Finding suitable housing that is affordable is another challenge for people with disabilities. There's not enough affordable housing, and this needs to be addressed by all three levels of government. There just aren't enough supportive housing options as well for people.

In summary, we acknowledge that the challenges facing individuals with developmental disabilities and their families are numerous and complex. We urge you to strive for a flexible, seamless continuum of services and supports for people with disabilities as they navigate life transitions and age. We encourage you to be bold in order

to enhance equity and fairness in the province. Ensure individuals have real options for creating a meaningful life in the community and for receiving the services they require through individualized funding and through responsive, person-directed services. Capitalize on the experience and the will to find solutions that exists amongst self-advocates, family members and agency staff. Together, we can create the future that we all seek.

Thank you for considering our recommendations.

The Chair (Mrs. Laura Albanese): Thank you very much. We have about a minute and a half for each party to comment or ask questions. We're starting with the government side. Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you so much for the work that you do. I know that you are a fairly large multi-service organization across Toronto, and you've really articulated the supports that you're providing specifically to individuals and families in this sector.

I want to thank you for sharing Victoria's story, as well. It really does help to put a face on the work that we're doing, which really is intended to strengthen our supports across a person's lifetime. I actually appreciate the fact that you focused on the aging side of things. That's something that we've touched on as we've conducted hearings, but it hasn't been, I think, as strongly articulated as you've done here today in terms of the complex needs and that report as well. I agree. I think we need to ensure that copies are shared with this committee and those recommendations factored in as we do our deliberations.

I just want to thank you for the work that you do, in particular the specialized work, such as women with development disabilities that have experienced abuse. You're focusing your resources on some of those areas that perhaps are overlooked, so I want to say thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones.

Ms. Sylvia Jones: Thank you for your presentation, ladies. I am not familiar with the DSO council's paper *The Crisis of Aging with a Developmental Disability in Toronto*, so perhaps we could get a copy of that for the members, because that's something that sort of comes up peripherally, but nobody is talking enough about it, and we should probably delve into it a little further.

1110

A hundred years—congratulations on your centennial.

Ms. Janet McCrimmon: Thank you.

Ms. Sylvia Jones: We're going to try to put together this combination of supportive family members and individuals who do not have that advocacy. That, I think is one of the challenges as we look at recommendations: How do they match both sides? I think what your agency is doing is a good example of that, so we have to figure out how we can take that model further afield. Thanks.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much for the presentation. Congratulations, and thank you very much, Ms. Parker, for Victoria's story. That really hit home.

Thank you for providing the figures, too. We're having a devil of a time getting figures out of ministries, so thank you for doing that. I understand that it's about 9,000 on the wait-list, which I think is what we're hearing from other agencies as well.

One of the figures that we haven't received and have asked research for is the number of folks with developmental disabilities who are in long-term care, where they shouldn't be. We've heard the figure of 4,500. We don't know if that's accurate or not. They're also in alternative levels of care, i.e. in hospitals, just sitting there, where they shouldn't be either. So that's something that we're looking for.

I have a question for you about Victoria. What will happen to Victoria once she's on her own completely? I'm just asking a question about the self-directed funding model and then how that will segue when she's on her own.

Ms. Patricia Parker: That's actually one of the things I would have loved to have been able to speak to and didn't have time for. In my submission, I have addressed that; the page is "Securing the Future of the Partnership." There I've spoken more specifically about what we're doing as a family rather than assuming or hoping that something will happen when we're no longer here.

As her parents and some other supporters, we're putting a number of things into place. Some things that people know about, like an RDSP and a Henson trust, are in place. We mortgaged our souls and bought her a little condo. It's paid for for her, so that guarantees her housing for a lifetime, as long as it's appropriate for her; nobody can boot her out.

We're working very closely with a disability lawyer, as well as working with Options and FST. We're working with PLAN Toronto in terms of looking at how we put together that next generation, and we're fairly far down the line, actually, in having identified people of Victoria's age or younger who are going to be trustees for her trust, people who know her personally and love her, who are agreeing to—I need me, you know? I can't find me. Some days I can't find me at all.

There are a number of people who know her well and who care about her, both family and not, and who love her and are stepping up to the plate, because we're asking them in terms of creating a circle of support, a network for her. That's what we're doing.

Ms. Cheri DiNovo: Thank you.

The Chair (Mrs. Laura Albanese): Thank you for adding that to your submission. That really helps us better understand what you are securing for the future.

Thank you for your presentation, once again.

Ms. Janet McCrimmon: Thank you for your time.

MS. NICOLE FLYNN

The Chair (Mrs. Laura Albanese): We now welcome Nicole Flynn, and we ask her to come forward. Good morning, Nicole. Please make yourself comfortable and start your presentation anytime you feel ready.

Ms. Nicole Flynn: Thanks. Good morning, members of the select committee. My name is Nicole Flynn. Thank you for permitting me to speak today.

Have any of you been told that you are not allowed to play on a team? I was.

Have any of you been told that you are not allowed to earn credits in high school? I was.

Have any of you been told that you were not allowed to enter a race? I was.

I was not allowed to do these things because I have Down syndrome.

Having Down syndrome doesn't stop me; society does.

When I was little I wanted to play t-ball like my brothers. I joined the same league as them. I needed extra help, and the coach looked right at me and said, "If she needs help, she can't be on the team." My parents were astonished to hear this, but they did not give up. They found other places where I was accepted.

I was eight years old when I learned about synchronized swimming. My life changed. At first, I trained three times a week. I worked hard. I had to learn to handle transitions and corrections, as well as the figures and elements, and put it all to music with a smile on my face.

My coach used to sign my routine to me as I swam because I couldn't remember my routine. I competed against athletes with a disability. Eventually, I was integrated onto a team of "normal" swimmers. For two years I competed against "normal" 16- to 20-year-old athletes. I did not win, but I had the challenge of competing against others closer to my ability.

In 2012, I was getting ready to go to Italy for the Down syndrome world swimming championships, but I had a problem. I did not have a coach to help me get ready. Imagine training for the biggest event of your life and not having a coach.

Another problem I had was money. I had to find a way to pay for my coach and for me to travel to Italy. I did not qualify for any funding because my international competition was not a sanctioned event. I guess for some people the world Down syndrome championships aren't important. But for me they are the Olympics. I swam on my own to get ready, and I fundraised by selling my wildlife photography. I held a draw for some of my framed photography. I also saved every dime I could to pay for my coach and me to get to Italy. That was hard work and stressful.

I represented Canada in the solo synchronized swimming event and Ontario in the speed swimming events. I was the only athlete in the world to compete in both synchro and speed swimming.

I won a world gold medal for Canada with my solo and two silver and three bronze international medals for speed swimming. The next competition will be held in Mexico in November 2014. Hopefully I will defend my gold medal. I'm up for the challenge.

My parents homeschooled my brothers and me because they wanted us to have a strong education. When I was 13, I wanted to go to high school. I went to an all-

girl school in the TDSB. It did not work out well. I was bullied and I was not allowed to take credit courses because I have Down syndrome.

I wanted to take courses that were interesting to me and earn credits as well. I left high school and completed the Duke of Edinburgh challenge. I learned to set goals for myself. I believe the more I achieve, the more I succeed. I enrolled at the Quinte Adult School when I turned 18 years old. This works well for me because I can move through the courses at my own pace. I have earned 20 credits so far.

1120

In the past I have done two triathlons. My coach wanted me to do the Welland Sprint triathlon because the course is flat. A flat course would be easier for me on my recumbent bike. I was not able to do the triathlon because they wouldn't accept my recumbent bike. It is hard for me to ride a two-wheeled bike because I don't have good balance and I have to be careful about my neck. This summer I started riding a two-wheeled bike with adult stability wheels.

I hope people in charge of the races will learn to accept people who require different equipment and permit them to enjoy the same privileges as everyone else. People of all abilities like to race and push the limits.

I hope to have a job one day. I would like to work at something that I enjoy, am good at and will support me. I know it will take time to learn to do a job well, but I have a lot of practice at hard work. I have volunteered for many years, and I am ready to be paid for my work.

I would like to live on my own one day. Right now I have to live with my parents because I don't have enough money to live in my own place, buy groceries and participate in society. I am also worried about being safe. People try to trick me and sometimes they make fun of me. I don't like that. I am careful with my money, but sometimes I need help counting the right amount. Sometimes people rush me and I make mistakes. I need extra time. It is not fair to rush people.

I have an extra chromosome but I have a lot of ability too. I have overcome many obstacles that people said I never would. It hasn't always been easy. I do not give up. I keep on trying. I have done many things in my life, and there are more things that I want to try.

The greatest challenge for me is that people think I am not able to do things. When people take the time to work with me, they get to know me and are able to see what I can do. I am a human being and I am capable of living a full life.

Now, I'd like to read my poem. It's called I Am Not Invisible. It was published by the city of Toronto in 2010.

People talk to me as if I am a child

I am an adult,

Look at my eyes and talk to me as an adult.

People treat me as if my feelings don't matter

I feel things,

I hurt inside when things happen.

People won't even let me try

I want the chance to try,

I might make mistakes; I will keep trying.

People do not see me; they treat me like I am invisible

I am here,

I want people to look at me.

People tell me what to do all the time

I can make decisions,

I am able to think for myself.

People treat me like I'm a non-person

I am a human being,

I am not a mistake.

Thank you.

Applause.

The Chair (Mrs. Laura Albanese): Thank you, Nicole, for your story of incredible success against all obstacles. I want to commend you for your determination, for your courage, and congratulate you for all your achievements—your medals and your achievements in education. But I have to go on to allow for questions. We'll have about three minutes for each party to talk to you.

Ms. Elliott.

Mrs. Christine Elliott: Thank you so much for being here, today. Nicole, you are awesome. It's unbelievable what you've been able to do. You've got a brilliant future ahead of you, I'm sure. It also sounds like you've got a pretty special family that has been supportive of you, too, and helped you every step along the way. You know, there are lots of people who do not even think about coming to sit up there by themselves and be as composed as you are, so it's wonderful of you to be here. You've given us a whole new opportunity, a new way of looking at things, that you're really going to make a difference for us in our presentations and in our decision-making at the end of it to create a report that's going to make sure that everybody has an opportunity to be the person they want to be and to do their very best.

Can you just tell me: What's your plan for the future? Where do you go from here?

Ms. Nicole Flynn: I'm hoping to be with my parents somewhere that it can be more supportive in respect for a different atmosphere that I can be most productive for myself and to society.

Mrs. Christine Elliott: Wonderful. Thank you very much for being here.

Ms. Nicole Flynn: You're welcome.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Nicole, you are truly a champion. I just want to thank you so much for coming here and talking to us. I couldn't synchronize-swim if my life depended on it, and I've never entered a triathlon. I don't think many people here around this table have. So you're our hero. Thank you for sharing those incredible accomplishments. You're an amazing young woman.

I just want to ask something of research. That is: We have, in Ontario, an act that is supposed to gain accessibility for people with developmental disabilities. I know that the date for doing that is way off in the future—I think it's 2025—but I want to know if that act covers

sporting events and athletic events, because I was very shocked to hear what you had to face when you just wanted to enter those sporting events. We need to make sure that sporting events, especially if they get public money, are open to everyone. That's something that I pledge that our committee will look at and take action on—because of you. So thank you.

Ms. Nicole Flynn: You're welcome.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you, Madam Chair, and thank you, Ms. Flynn, for your very powerful and excellent presentation. I think that what you're doing is absolutely amazing. You're a wonderful ambassador and inspiration to all of us. I really want to commend you on all of the achievements that you've had in your life and those that are ahead. I know that there are many great things ahead of you.

I notice here that you are interested in getting into the labour market and to find paid work. Are you participating in any of the social enterprise programs or in any way connected to organizations that could help you do that, and to achieve that goal that you've set for yourself?

Ms. Nicole Flynn: Well—

Ms. Kathryn Primrose: Can I step in?

The Chair (Mrs. Laura Albanese): Sure. Please come forward.

Ms. Kathryn Primrose: I'm her mom.

Ms. Nicole Flynn: Kathryn Primrose is my mother.

Ms. Kathryn Primrose: You lost her at "social enterprise."

The Chair (Mrs. Laura Albanese): You can have a seat.

Ms. Kathryn Primrose: What do you want to do for work?

Ms. Nicole Flynn: I want to work. There's a lot of stuff that I want to work at. One of them is speaking to you guys, which is my strength—

Ms. Kathryn Primrose: Being a speaker.

Ms. Nicole Flynn: —being a speaker, and—I don't know what else to think of.

Ms. Kathryn Primrose: You've been talking about Pet Valu.

Ms. Nicole Flynn: Yes, I was thinking about doing Pet Valu and maybe work in their shops.

Ms. Kathryn Primrose: And your photography business?

Ms. Nicole Flynn: Yes. I do photography at Madoc market up in northeast—

Ms. Kathryn Primrose: She has her own photography business where she sells her wildlife pictures.

1130

Ms. Nicole Flynn: And it's actually called Flynnster's Pictures.

Ms. Kathryn Primrose: Flynnster's Pictures.

Ms. Mitzie Hunter: That's wonderful. So you actually are creating your own employment and are an entrepreneur. That's wonderful. So good.

Ms. Nicole Flynn: Thanks.

Ms. Mitzie Hunter: Thank you so much.

The Chair (Mrs. Laura Albanese): I want to thank you once again for coming to speak to us today and I also want to wish you all the best for the next competition in Mexico in November of this year to defend your gold medal. All the best. We'll be rooting for you; we'll be cheering for you. We hope you defend Canada and defend with determination all you have earned. Good luck.

Ms. Nicole Flynn: Thanks.

Miss Monique Taylor: Let us know how you do. We'll be rooting for you.

Ms. Nicole Flynn: Will do.

The Chair (Mrs. Laura Albanese): Yes, we'll be in touch.

Ms. Nicole Flynn: Thanks.

ONTARIO AGENCIES SUPPORTING INDIVIDUALS WITH SPECIAL NEEDS

The Chair (Mrs. Laura Albanese): We'll now ask the Ontario Agencies Supporting Individuals with Special Needs—OASIS—to come forward and make their presentation. Good morning.

Ms. Jane Joris: Good morning.

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes to make your presentation, and if it should be any shorter than that, that would allow for comments and questions from the members of the committee. You may begin at any time.

Ms. Jane Joris: Thank you very much for the opportunity to address the committee today. My name is Jane Joris and I'm the president of Ontario Agencies Supporting Individuals with Special Needs, or OASIS. I'm joined by our vice-president, volunteer, David Barber, and vice-president and executive director, Allan Mills.

OASIS is a volunteer-run, member-driven organization. Our member agencies serve over 65,000 of Ontario's most vulnerable citizens and employ 25,000 full- and part-time staff. Our 172 member agencies currently provide more than 85% of all developmental services funded by the Ministry of Community and Social Services and receive approximately \$1.4 billion in operating funding annually from the Ontario government.

In addition to our work with OASIS, each of us is involved in other roles in a different part of this province. I work as an administrator of a long-term-care home in Lambton county and as a volunteer with Lambton County Developmental Services. Both David and I have family members who have intellectual disabilities. David Barber serves as president of Simcoe Community Services, and is also a business owner. For his part, Allan Mills serves as vice-president, Ontario, of Christian Horizons, Ontario's largest provider of developmental services.

I mention this in the interest of full disclosure, but also by way of highlighting the hard work and double volunteering duty that so many in the developmental services sector are known for.

Perhaps most importantly, these multiple hats give each of us the ability to understand the challenges facing developmental services both in our communities and at a provincial level.

We have seen first-hand countless families struggling to make ends meet and having to make decisions that most Ontarians would never have to contemplate. We have seen families languishing on wait-lists forced to leave their jobs in order to care for a loved one. We regularly encounter adults with developmental disabilities living with aging parents whose own health challenges are exacerbated because their retirement savings have been depleted and they are no longer able to support the daily needs of their child or themselves. Worst of all, we have seen many declare themselves broken and make the heart-wrenching decision to leave their child on the doorstep of a service provider.

We are deeply embedded in the economy of the province, and we see first-hand every day how the level of unmet investment in services for Ontarians with developmental disabilities results in a loss for every taxpayer. This economic loss is not only felt at the front end when family members are forced to quit their jobs to care for loved ones on wait-lists; ultimately, unmet needs of this nature evolve into crisis scenarios and end up costing taxpayers even more on the back end in costly band-aid solutions. A lack of preventive services is inextricably linked to more crisis situations, which ultimately drives up the cost to taxpayers.

It's clear that the needs are great and the resources are limited. We are now at a breaking point. Existing services alone face a funding shortfall of \$100 million by 2015-16. That figure does not take into account the 12,000 to 20,000 Ontarians with developmental disabilities currently on wait-lists.

Ontario's approach needs to be one that engages a village in an integrated strategy. A holistic solution must reach beyond the parameters of services provided solely through the Ministry of Community and Social Services, in a way that follows the path set out by the principles of the Accessibility for Ontarians with Disabilities Act, the transformation agenda and the service improvement recommendations outlined in the 2012 report commissioned by the Ministry of Community and Social Services, *Brighter Prospects*, which reviewed social assistance in Ontario.

Today we would like to touch upon some of the presentations that have already been delivered to this committee, and, in doing so, help to demonstrate that solutions for the developmental services sector are within reach. With proper planning, people in need of support can transition into less expensive situations, connect to more informal supports and take control of their lives.

Mr. David Barber: Many of our member agencies have appeared before you, outlining the ways they have stretched limited resources cost-effectively and responsibly to build more capacity in their local communities and modernize service delivery. Our members have been responsive and responsible in doing their part to help

mitigate the financial challenges of the province, while continuing to honour commitments to our most vulnerable citizens.

As a sector, we have championed the challenges in many creative ways—ways that have built partnerships and collaborative approaches, forging inroads to access in five critical developmental services success areas: providing housing, employment, respite care, knowledge sharing and leadership development.

I want to reiterate just a few examples you have heard of our member agencies and their long record of great care, service quality and ensuring bang for taxpayers' buck:

Community Living Toronto has the Lights alternative housing model;

Community Living Essex County has partnered with the city of Windsor and the Ministry of Municipal Affairs and Housing to provide affordable housing;

Community Living Tillsonburg has partnered with the Ontario Disability Employment Network to promote and find employment opportunities for individuals with disabilities;

Christian Horizons has created a family retreat through fundraising and through volunteerism;

Kerry's Place Autism Services has provided specialized services for individuals with autism in collaboration with schools and families, while Ottawa Rotary Home has provided leadership in development of an agency collaborative to provide a community nurse consultant;

Participation House Project (Durham Region) has developed models of transparency and accountability that engage all employees in financial decisions;

Community Living Owen Sound and Community Living Walkerton and District have created a model to share the expertise and oversight of one executive director.

Mr. Allan Mills: In an environment where urgent problems consistently trump important structural issues, little money is allocated for preventive and proactive services. Funding based on crisis alone will ensure that waiting lists continue to grow, that we fall further and further behind, and the burden to taxpayers continues to skyrocket. Continued referral of our families to other public support models, the costs of which are far greater than what could have been provided through developmental services, is unsustainable.

Perhaps most unjustly, many of those on waiting lists and facing crisis are people who have kept their kids at home, founded agencies and services for others, and now find that there is no support available for them. The positive news is that we can stem the negative tide immediately, using a two-pronged approach that addresses a growing backlog of crisis care while also proactively investing in preventive solutions to stop crisis situations from germinating in the first place.

1140

First, we must commit to proactive systems changes. For example, many of our member agencies have legislated pay-equity commitments to their staff. In a frozen funding environment, services will continue to be eroded

as agencies struggle to meet these legal requirements. At no cost to the government, the province should delay this pressure to ensure that services are not compromised.

Additionally, many of our member agencies deliver services on an ad hoc basis with no government commitment to fund the services beyond the current fiscal year. An inability to plan more than one year ahead means that agencies lack the ability to fully apply localized expertise to ensure cost-effective service delivery.

Because our members have proven their worth in terms of stretching every dollar, it is time to repay that faith by giving them more responsibility and opportunity. The budget process must allow for the creation of reserves, similar to community counterparts funded by the Ministry of Health. Transfer payment agencies should have four-year rolling budgets, with appropriate accountability measures, for the purposes of establishing reserve funds to fund capital projects and major repairs, and to develop innovative, cost-effective programs in a planned manner.

Second, additional investments are needed to ensure that critical and immediate needs are balanced with the imperative for preventive and proactive services. The province must commit to a one-time investment to stop the mounting crisis situation created by four consecutive years of no additional funding to sustain existing services or even to provide an annual cost-of-living increase.

Third, we must prioritize inter-ministerial and cross-sector collaboration. Prioritizing collaboration across ministries such as the Ministry of Training, Colleges and Universities, the Ministry of Health and Long-Term Care, the Ministry of Labour and others is the only way to develop an integrated strategy to address poverty and the need for accessible and affordable housing, and to ensure that every person who has a developmental disability and their family has access to the support they need. The Ontario Partnership on Aging and Developmental Disabilities and the Ontario developmental services human resource strategy are but two successful examples of a type of inter-ministry programming that we desperately need more of.

Ms. Jane Joris: On behalf of OASIS's 172 member agencies and the thousands of Ontarians that we support, I want to thank the members of the committee for your time today. We are happy to delve into further detail in the question-and-answer time and elaborate on the three solutions we've briefly outlined, solutions that will allow volunteers in our member agencies, who are experts in the field and who have already demonstrated to you over and over again a capacity for stretching every dollar to deliver high-quality services, the opportunity to address both critical and preventive service needs. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you. We have about two and a half minutes each for questions. Ms. DiNovo?

Ms. Cheri DiNovo: Thank you very much for your input here. Of course, it just builds on everything that we've heard from every other person who has come for-

ward as a witness, so there is a wonderful—sad, but wonderful—congruence between it all.

The multi-year commitment model, we've certainly heard before, and it makes some sense. You don't spend all your time reinventing the wheel. In terms of the pay equity, we've certainly heard that before, that legislation.

Again, the wait-lists seem all over the map. We don't seem to have concrete data. We are saying 12,000 to 20,000; that's a gap of 8,000, so we don't even—this is a great shortfall of the ministries, I think, if we don't even have accurate figures to work with on that.

You perhaps heard me say earlier that we would really need figures on how many people are in alternative levels of care, waiting in hospitals and in long-term-care homes, where they shouldn't be—that whole sector, because essentially what that helps us to do is make an economic argument for proactive planning, which is what you're calling for, because we are crisis-funding now. By doing so, we've created a crisis; that's very, very clear. So we have to get away from that, and to do that, just to find even the figures that we need is difficult. That shows how far behind we are.

I want to thank you for all the good work you do, and your member agencies are phenomenal. We've heard from many of them. I particularly made notes of some of those special—like Lights and others, some incredible creativity when families get together and start to think and plan. Thank you.

Ms. Jane Joris: Thank you.

The Chair (Mrs. Laura Albanese): We'll pass it to Mr. Balkissoon.

Mr. Bas Balkissoon: Thank you for being here and for all the work that you do in the communities.

There's something I heard you say, and I'm not sure I heard it exactly correctly, but a lot of your member agencies have been here presenting, and you're here. Has there been a collective report with some major recommendations that the government can look at, rather than us going through all of it and having to put it together? Because you're the experts.

Ms. Jane Joris: We have not done that. I believe that the provincial network has done a little bit of work on that, so we can speak with them and see if they've got something together. But we have not done that.

Mr. Bas Balkissoon: Is there any possibility of something collaborative being done before the committee finishes its work?

Ms. Jane Joris: The provincial network meets on Thursday, so we could speak with them then, for sure.

Mr. Bas Balkissoon: Thank you. I'd really appreciate that, because we've gone through piles of documentation. I think yours would be more focused, because you've basically made some comments that some of the changes necessary can accomplish a lot. I'd love to make sure that we consider them.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones.

Ms. Sylvia Jones: It's good to see you again. Thank you for your presentation.

I have to say, I really am glad that you raised the fact that we almost are punishing families who were willing and able to support their children in a family environment by the situation we're faced with right now with the wait-lists and the "Come back later" concept.

I have a question for you. You were very diplomatically silent on any comment about the DSOs. I wonder if you could share with the committee your thoughts.

Ms. Jane Joris: A number of our members are DSOs, so we're working with them to help them with the struggles they are facing. We do recognize that we don't have the informal contacts with the people who are waiting for services that we used to have, and I think you've already heard about that in a number of presentations. We recognize the struggles and we recognize it's a huge change in how the sector works. There are definitely some problems, and we're trying to work with the DSOs to help them work on that. We meet regularly with the network of the DSOs as well.

Ms. Sylvia Jones: Are you finding that the DSO rules are being applied consistently province-wide?

Ms. Jane Joris: Probably Allan can speak to that better, since their organization is provincial.

Mr. Allan Mills: Sure. I work with Christian Horizons, and we work with all nine ministry regions—I guess it's five now, but there are nine Developmental Services Ontario organizations, and my organization works with all of them. There is a fairly vast range of how they do their work, considering that the intent of the system has been to standardize access across the province. In some regions it works quite well, and where it works best, there's a collaborative approach that involves the developmental services organization along with the service provider agencies, working strongly together. We see that in several of the regions.

In some, there seems to be more of a sense of barrier and isolation between the families that need services and the service provider organizations. Like Jane mentioned, historically, there would be some informal relationships developed over a period of time, maybe informal supports provided while waiting for the more formal supports, but it's harder to do when there's a step in between the families that need the services and the service provider. Things are much more tightly monitored in terms of services. We serve a certain number of people according to our service contract agreement with the ministry, and for us to essentially informally serve more people kind of takes away from the people that we're officially funded to serve. So it helps if there's some creativity and flexibility in that process.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you once again for presenting to our committee. I guess we'll look forward to that more comprehensive presentation that will sort of summarize all of your suggestions and recommendations.

Ms. Jane Joris: Okay. Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you so much.

We are recessed until 1 p.m.

The committee recessed from 1150 to 1304.

CUPE ONTARIO

The Chair (Mrs. Laura Albanese): Our committee is back in session, and we are calling on our first presenter of the afternoon, CUPE Ontario. President Fred Hahn, how are you? Good afternoon. You can start any time you're ready. You will have up to 20 minutes for the presentation.

Mr. Fred Hahn: Perfect. Good afternoon. My name is Fred Hahn, and I'm the president of CUPE Ontario. With me today is Sarah Declerck, who is the coordinator for our social services in Ontario for our union.

I should also tell you that a number of CUPE members who work in developmental services will be appearing before the committee to bring you a more in-depth examination of the experience that they have in different community agencies.

Let me begin by saying that CUPE welcomed the establishment of the all-party select committee and its mandate to develop a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability. We very much appreciate the opportunity to appear before you today and to deliver a submission on the state of the sector and our proposals on a way forward.

I want to stress that this analysis and the recommendations contained in our written submission, which is on the way—sorry, it got caught in traffic—is based on the broad experience of our many years in the developmental services sector across Ontario.

CUPE has the privilege of representing 8,000 members who work in developmental services in 55 different community agencies. In fact, prior to becoming CUPE Ontario president, I also had the privilege of working in this sector for well over a decade.

The sector has evolved and changed dramatically over the years, and our union's members have been there at every step. CUPE members working in developmental services care passionately about the work they do with the individuals and families they work with every day, and they are looking to you, the members of the select committee, for leadership in this sector, which desperately is searching for a champion. All of us look forward to your report and hope that it reflects our combined efforts and that our efforts will make a contribution to that.

Overall, the developmental services sector, from our view, seems to face two big challenges, the answers to which will be the core components of the comprehensive developmental services strategy that you have been tasked to find.

The first is about funding and the second is about ensuring that the design of a support system that we provide is shaped by the needs of individuals, families and service providers and not by the dictates of any one or other political or fiscal agenda.

Let's start by talking about funding. Although it suffers from overuse in some discussions like this, the word "crisis" seems appropriate to describe the facts in developmental services in Ontario today. There are at least 24,000 families on wait-lists for residential care, respite care and day programs—24,000. Is that a crisis? For the families on those wait-lists, I suspect it is. And it does get worse. According to a recent survey done by OASIS, an association representing agency employers, 62% of responding organizations have cut staff hours, 51% are eliminating staff positions, 58% are not filling open positions like maternity leaves, 18% are reducing program hours of operation, 7% are permanently closing programs, 16% are shutting down programs for a specified period of time, 28,000 staff hours per week and 665 program hours per week have been eliminated, and 42 programs have been temporarily closed. Some 65% of agencies surveyed reported that as a result, they're able to provide less individualized care, fewer specialized services, a decreased prevention service ability, elimination of recreation activities and community outings, elimination of quality-of-life activities, and being forced to introduce new user fees for transportation and day programs.

What conclusions can we draw from this information? Remembering that we have a steadily growing and aging population, the most logical conclusion would be that provincial funding supports for Ontarians with developmental disabilities have obviously not been sufficient to prevent reduction in service levels. Even when we take into account one-time injections of \$220 million in 2007 and \$42 million last year, what we see is simply a failure to keep pace with growing demand. We see an actual reduction in services.

Let's be frank: Reduced services mean cuts. I'm sorry; there's no better way to describe it than to say "cuts" when we talk about reduced hours, eliminated staff positions and closed programs. I stress this because in our experience with the ministry, we've been repeatedly told that there are no cuts because government has delivered funding increases. The facts would say that whatever increases may have been delivered have not been sufficient to prevent cuts in service levels and programs, and we have an obligation to do better. That's what adults and children with developmental disabilities and their families need to hear in your report, and it's also what CUPE members and everyone else involved in providing these supports is looking for you to say. They need this all-party select committee to be unequivocal in its report, that when it comes to supports for children and adults with developmental disabilities in the province of Ontario, reduced hours, eliminating staff positions and closed programs are not something that we're prepared to live with, nor should it be accepted by any government of any political stripe in Ontario in 2014.

1310

The second major issue facing this committee is about strategic design. What model of support system is best for persons with developmental disabilities and their

families? We all know that in Ontario, the model has changed and evolved over decades, and it's still evolving. While the move away from old institutional models was necessary and overdue, there is today a pressure that threatens to go too far in another direction. Driven more by political dictates than by the needs of Ontarians, there is now a pressure to undervalue the degree to which individuals and families need the organizationally structured support that only an agency model can provide.

The number of individuals who need agency and residential supports is increasing, not just because our population is growing, but because the parents of developmentally disabled children and adults are themselves growing older and, as such, are less able at home to provide those supports even when they have accessed Passport funding or by accessing a measure of respite care. Just looking at the relative size of the wait-list leads us to the same conclusion. The number of people waiting for agency residential supports is not shrinking, but is, in fact, much larger than the number of people waiting for respite care or individualized direct support that comes through Passport. And it will only ever more so increase in the years to come.

This is even more so true when we look at the numbers and understand that many families, when they've come forward asking for support and put their names on a wait-list for Passport, have done so because they've been told that if they only wait for a residential space, they could wait forever. Facing up to that reality should make it clear that the strategy of the slow starvation of our agencies is wrong-headed and should not be part of the direction this committee charts for the future.

But this is not a discussion about a growing and aging population only; it is about the model that is best suited to deliver services that Ontarians need. Is it just a coincidence that as more agencies are starved to the point of cutting hours and programs, and there are longer waiting lists for residential spaces, the more vulnerable the agency model becomes to the charge that it is no longer the best model for service delivery in the sector?

What I've learned—what thousands of other CUPE members working in the sector have learned over the years—is that residential support cannot be replicated through individualized funding models like Passport. In fact, not only is the agency model capable of providing support based on individual need and program design, it is the best model to do that. Why? Because it brings together the broadest range of talent, experience and resources. It does things that no individual family or service provider could do working alone. It is efficient precisely because it makes possible economies of scale.

Let me be clear: CUPE is not here today to say that Passport should be eliminated or the DSO shut down, but we are here to say that the funding balance is wrong. The emphasis is wrong, and it is past time for a rethink of our model of service delivery in this sector.

It's time to recast the model such that it reflects the reality of developmental services and meets the real needs of Ontarians. Doing that in an honest way, in a way

not driven by dictates of a crusade against the provincial deficit, will lead to an appropriate valuing of the organized agency model and, accordingly, an appropriate approach to funding.

In conclusion, I want to be very direct: What CUPE is asking of this committee—and I believe what Ontarians with developmental disabilities and their families and indeed all service providers are looking for from the committee—is for you to find the political courage to say something that has become very difficult to say in Ontario. We need to say that there are times when some priorities in a civilized society must stand above any short-term pressure to achieve a balanced budget. Meeting the needs of our friends and family members with developmental disabilities is one of those times. If you can find your way to that conclusion, you will have done a great thing for Ontario and you will have made a lasting difference for thousands of families.

Thank you, and we'd be pleased to take any questions.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We have about three minutes for each party. I'm going to continue where we left off, so it's the government's turn to start the questions.

Ms. Mitzie Hunter: Thank you so much for your presentation. I know that the handout that you provided has more detail and background that will help to inform our work. As you know, this Select Committee on Developmental Disabilities was struck to respond to the needs and to ensure that we have the supports across a lifetime for a person with developmental disabilities and dual diagnoses, but also to ensure that there is inter-ministerial coordination and prioritization. That is the mandate. That's what we're here to do. We have been talking to many families, individuals and organizations across the province. Many of your members have provided really valuable input.

I see here that on page 15, you have a number of recommendations in terms of what the sector needs. Is there a particular—I won't ask you for one, but are there any of these that you feel are of greatest importance for us to consider?

Mr. Fred Hahn: Thank you for calling attention to some of the more concrete recommendations. I think, from our perspective, many of these are interrelated. As I said in my presentation, what we try to do is characterize both the challenges around funding, because there seems to us to be a clear need for additional funding in this sector, but also around the model in which that funding is disbursed and utilized.

Some of the other things that we've pulled out here speak to the way in which we can best provide supports for people with developmental disabilities, based on the experience our members are currently seeing, but also the experience they've had over a number of years: for example, having the right staffing ratio to deal with particular challenges and particular individuals to ensure that that ratio allows for community integration and all of the other things that our agencies and that many of us are mandated to provide and to ensure and to facilitate for

people with developmental disabilities. In many ways, these are all tied together in some way.

It's good to hear that the work of the select committee has already been important in ensuring some inter-ministerial coordination, because for young people who reach an age where they're no longer able to access certain supports and enter the adult realm, there is a challenge in that transition, and the more focus that we can place there and the preparation for people is quite important.

Again, all of these things in some ways are linked, but in some ways it also goes back to the fundamentals, which are: How will we fund the service and what is the model in which we're funding it? It's why we say that we believe strongly in the ability of agencies to bring together the kind of expertise and support that families truly need.

Ms. Mitzie Hunter: We've heard so much from the families with children and adults with developmental disabilities and there seems to be the need for both, that families want to be able to provide that natural support, but they need the help and the relief to do that. Can you talk about what your members are seeing in terms of what families are asking for the most?

Mr. Fred Hahn: I think it depends on the particulars of a family, naturally, but there are increasing numbers of aging parents who have, for many years, cared for their adult child with a developmental disability. Those supports for those families are in fact more critical. But one of the challenges we have in this sector is that in fact that's where we're at: You have to have a crisis before people can access the kind of supports they need, rather than making a plan that will help people to access these kinds of supports in a way that isn't based on crisis but is actually based on what's best for the individual.

1320

In the experience that I had in the agency that I worked for, one of the things that we were engaged in at that time, and that was some years ago, was this real work with families to ensure that we were working together for the best interests of the individual with a disability, and that we could be providing the kind of supports necessary. But that was always limited to how many staff we had, how much we could do for that family. Increasingly, people were left with small amounts of respite care, which provide some support to a family but aren't the kind of comprehensive care that's required to plan into the future for anyone with a developmental disability.

The Chair (Mrs. Laura Albanese): Thank you. I'll pass it now to Mrs. Elliott.

Mrs. Christine Elliott: Thank you very much, Mr. Hahn, for coming before us with your presentation and your recommendations. We really appreciate it. We have heard from some of the agencies in some of the travels that we did last week, but I think this is the most comprehensive piece that we've seen so far.

One of the things that you talk about in your recommendations is to let people know the extent to which

people are being held in inappropriate locations, like long-term-care facilities, hospitals and jails. I agree with you entirely. That's much more expensive care to begin with, but also, more importantly, it's not appropriate care. We should be making sure that we only use that as an option where there's absolutely nothing else available.

But I think there is no question, at the end of the day, that this is a sector that is under-resourced and that is going to need some assistance across a whole range of activities, from housing to respite to day programs and so on. I think that what you've brought forward makes a lot of sense. I think you'll find that the members of this committee all feel the same way. So we look forward to working with you in the future.

Mr. Fred Hahn: Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you for the presentation. It's very succinct.

In the recommendations, one of the interesting ones—you say it directly, what so many others have inferred—is that the money that goes to the DSO could be better spent. That was welcome.

Number two: What you've said here, which I've constantly been asking for, are examples of where it's done better. It's interesting that you mention Saskatchewan and Australia, because those are two that have come up again and again. Particularly interesting in a sense, especially because it is, of course, not a left-leaning government in Saskatchewan, is the mandated end of wait-lists. I think if you mandate, the money flows; if it's entitled, the money flows. If it's discretionary, it doesn't, and that's what we're seeing here. So the different systems, the discretionary, i.e. welfare kind of systems we're used to, or entitled, as in health care, are two very different systems. We're not sure that what's working here is the discretionary one, which is what we've got.

So I thank you for all of that as well. Again, I think, like Mrs. Elliott said, we're on the same wavelength here. Thanks.

Mr. Fred Hahn: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much once again for the comprehensive presentation, and we'll leave it at that for now.

Mr. Fred Hahn: Great. Thank you, and thank you for all of your work on this committee.

The Chair (Mrs. Laura Albanese): We appreciate your input.

DEVELOPMENTAL SERVICES TORONTO COUNCIL

The Chair (Mrs. Laura Albanese): Next we're calling on Jasmin Earle and John Mohler. We had a change in the names, and I guess the Clerk would enlighten us. He just made a change on my agenda.

Welcome to our committee. You will have up to 20 minutes to make your presentation. If there is time left over, then we will have some comments and some ques-

tions from the members of the committee. You may begin any time you feel ready.

Ms. Jasmin Earle: Okay, thank you. First of all, thank you for giving us the opportunity to come before you. Let me just introduce myself. I'm Jasmin Earle, and I chair the Developmental Services Toronto Council. The DSTO Council is made up of community volunteers, board members from service provider agencies, family members who are using services and self-advocates who are service users who are supported by facilitators to participate on council. We also have representation from the ministry, and we have representation from the service provider committee of the DS Toronto partnership, which is all of the service provider agencies working together in a collaborative.

Council's primary role is to advise the ministry and advise service providers around issues that are related to the delivery of services within Toronto. So what we brought today was something that were really system challenges and pressures which we thought were relevant to the role and mandate of this committee. We didn't bring forward specific challenges that are unique to Toronto because we already have the opportunity to work within that system on service delivery improvement.

Council has representation on standing committees of the DS partnership, such as improving quality information and planning. We also participate in task forces, ad hoc work groups, and we also have our own council working groups, which include members of council, but also external resources and experts, including academics, who work with us on working groups that are linked to the priorities that the council has identified around making improvements to the service system.

Sorry—I just have to now get back to my notes, because that was sort of ad hoc.

Three years ago, DS council struck a working group, and this working group was really in response to much of the community engagement and stakeholder consultation that we had done, because we see part of our role as giving voice to service users and providing a forum and opportunities for them to bring forward their priorities.

A priority that we were hearing over and over again was related to aging caregivers and aging service users, and some of the challenges that people were experiencing as they aged in continuing to provide either complementary services and/or being exclusively the caregivers of their adult children with developmental disabilities who were also aged.

Our working group was struck three years ago, and we developed a report. The report that you have before you is the product of that working group. It was also shared with the Ombudsman during the recent inquiry. It's also a report that has come through support from our collaborative, so that the ministry and our service provider partners are aware that we're bringing this report before you today.

I'm going to let my colleague John Mohler, who is a member of council but also a member of the aging work group, to run through some of the highlights of the re-

port. Then, at the end, we have some recommendations. Those recommendations are contained at the back of your report.

Mr. John Mohler: Thank you. I'll hope my voice holds out. I have an appointment with my surgeon tomorrow at St. Mike's, but we'll soldier on.

I should add that, in addition to being a member of the council on the work group, I'm a parent. My wife and I have four children, three of whom were born blind. Of those, our two eldest sons, 34 and 33, are also non-verbal. They have a dual diagnosis. They both understand the world as someone much, much younger. Their contribution to the community has to be considered in quite a different manner. We also have a 28-year-old daughter, who is blind and has a master's degree from the University of Western Ontario.

Having read some of the transcripts that have been presented, especially those of parents, what we're going to talk about will undoubtedly come as no surprise to you. You've heard heartfelt stories. Families will have the issue of aging to deal with, not only the aging of their children, but their own aging.

It's difficult to establish the prevalence of developmental disabilities within a population, but the best evidence at the time of our report indicated that somewhere between 1% and 3% of Ontarians are developmentally disabled. So that suggests that within Toronto there are between 25,000 and 75,000 people with some level of developmental disability.

1330

How many of these individuals are receiving service from the 37 agencies within the metropolitan area that are funded by MCSS? Statistics available when we published indicate that there are just over 12,000 individuals receiving services. That leaves, as you can see from the other numbers, a large hidden population of more than half who are unknown to the system, who are unidentified. They will need services at some point, likely when a crisis arises, and likely when their parents can no longer take care of them. Of those 12,000-plus receiving services, 1,920 receive some kind of residential support—that could be a group home, semi-independent living or some other support.

Also, we know that in Toronto there are 2,296 individuals on the waiting list. Caregivers for 207 of these individuals are between the ages of 71 and 80, and 112 are between 81 and 90. And shockingly, for 22 of those individuals, their caregivers are more than 90 years old—these are people living at home with a parent more than 90 years old.

Ontario has made great strides over the past 20 years in the advancement of care for people with developmental disabilities, especially as it relates to living within a community as opposed to living within institutions. However, this also comes at a cost to the family home, exacerbated by existing demographics.

With our aging baby boomers, as well as longer lifespans, comes a two-pronged dilemma. As the parents of individuals with a developmental disability age, their

capacity to care for their children diminishes as their own health declines—and as they die. As adults with developmental disabilities get older, the onset of age-related change often occurs earlier than otherwise, and typically would require more extensive—and, therefore, more expensive—care. For example, among people with Down syndrome, the mean age of death rose to 56 by 1993, up from an estimated nine years in the 1920s.

US studies suggest that the total population of people with developmental disabilities age 55 and over will double by the year 2030. Compounding these changes is the fact that there is a higher prevalence of early-onset dementia within this population, including those with Down syndrome.

Additionally, a recent study showed that in Ontario, over 45% of adults with a developmental disability have received a psychiatric diagnosis, a dual diagnosis, during a two-year period.

From the statistics that we've prepared in the report and summarized somewhat here, we can estimate that somewhere between 85% and possibly as much as 95% of the day-to-day care for people with a developmental disability is provided by those individuals' parents and/or families.

Here are some highlights of several cases that are identified within our report.

Ms. Jasmin Earle: Mary is an 84-year-old woman living in a one-bedroom apartment with her 85-year-old developmentally disabled brother. She has been her brother's primary caregiver for almost 30 years. The CCAC provides some support, as well as a day program and some occasional respite service. However, Mary's health is declining, and she worries about her brother, who is very reliant on her. She is also unhappy with their current level of supports, where they rely on a revolving door of workers and support staff coming in and out of their home.

Another story is of Carol, who is 77 years old and has a 57-year-old daughter, Karen, who is developmentally disabled. There is no long-term plan for Karen, who is currently involved in an occasional respite program, as well as a social program once a week. Carol feels trapped as the caregiver, and she herself doesn't want to go into long-term care because she has no place for Karen. She would like to see Karen settled into a group home.

Does long-term care fit into the equation? Well, yes. The Ontario Partnership on Aging and Developmental Disabilities, known as OPADD, is a partnership between the developmental and long-term-care service systems, with the goal of coordinating an approach to supporting people as they age. They've had some success, and we recognize that their focus on bridging the developmental and long-term-care sectors is an essential step in helping people to address the issues surrounding aging within our population.

The sectors must use each other's resources and must coordinate their response so that people can remain in their homes if they wish and are able. And when it is appropriate, the application process for an individual with a

developmental disability into a long-term-care facility is no better than the process for the rest of the population.

So with over 20,000 at any given time waiting for a long-term bed in Ontario, the availability of specialized care required for this population remains severely restricted and with very inequitable access.

Mr. John Mohler: To assess the current level of service on the part of the 37 Toronto-based agencies, we conducted an online survey in April 2012; 24 of those agencies replied. You'll see their detailed responses in our report; that's appendix B.

To summarize, the report was based on individuals over the age of 40. Highlights are that 70% of the agencies who responded are providing some level of support to individuals over the age of 40; 16 provide residential support and 20 provide non-residential support. There's some overlap between those two numbers. There are 10 agencies considering or developing new supports to those over 40. Four agencies have a staff committee devoted to aging, and nine agencies in Toronto have made a referral to long-term care in the past year.

The good news is that since presenting this report to the Toronto-based agencies, a task force—a subset of these agencies, along with others representing the DSTO—has been struck to strategize a coordinated approach to the issues of aging within our population. The task force has its first meeting scheduled for later this week.

Ms. Jasmin Earle: In our research into other jurisdictions, both within Canada and elsewhere, we can truthfully say that we didn't uncover any innovative solutions to these issues. What we found was that there was a general consensus that there is a crisis associated with this population's aging and the aging of its caregivers. Even with a wealth of academic studies and discussion papers, there have been no particular solutions that seemed viable that have been presented.

In our opinion, there's an opportunity for Ontario to lead the way. With our universal health care system, there are systems in place to promote a sustainable system of family and community care.

We'd like to make the following recommendations to this committee, which we obviously sincerely hope that you will adopt. We want to develop a strong partnership between the ministries associated with services to the developmentally disabled and to the aging population. We're obviously identifying the Ministry of Health and MCSS as two obvious ones, but really, adults with developmental disabilities are accessing services and are supported by a variety of service systems supported by a variety of ministries.

We also want to see that linkage established with the CCAC. We think that with that level of coordination between funders and between systems, there will be an opportunity to build solutions that will provide the necessary supports that these populations need. We recognize that one change, even a small change, in one service system has a ripple effect on other systems. We are very mindful of the demographics in the general population

and the aging of our population as a whole and the cries for fiscal restraint and for other kinds of financial limitations on ministries.

1340

However, we still feel that a coordinated approach presents the most viable opportunity. An example of this could be using a long-term-care facility to house an aging parent as well as their developmentally disabled adult child. While recognizing that the needs of both within the facility would be different, nonetheless supports around staff training and strategies around managing behaviour could be provided by the DS sector to the long-term-care sector.

We want to ensure that planning for the aging population takes place. At the moment, the ministry has no robust data to quantify the hidden population, and neither is there good data available to support system and service planning around what the existing needs, as well as the emerging needs, are of the people who are served within the service system. Certainly, this data is not shared at the tables that we are at, which is a collaborative between service providers, the ministry and the community.

Even the hidden population who aren't currently availing themselves of services will at some point become frail, aged, face a financial crisis and/or face a health crisis that will force them to access the service system, and, currently, the service system will not be able to respond. The best that can be done is that some intake will take place and they will join a waiting list, which has many thousands waiting for service.

We want to continue, as this committee is currently doing, to engage parents, professionals and agencies in working together around solutions and ideas. We certainly look forward to any recommendations that may come forward from this committee's work, with the hope that you will have heard from many, many stakeholders and that there must be some viable ideas within that consultation.

We want to begin formal discussions about the shared funding responsibilities. As people age, their health needs will grow quickly, and far more quickly than the DS supports that are available. We would like to see a system that develops age-adjusted funding so that the funding needs that provide services can keep abreast of the changing needs as the adults receiving services age and as their primary caregivers age too. And we'd like to reinforce the flexibility in the direct funding model to facilitate alternate models of care for aging at home.

That's the end of our presentation. We look forward to any questions that you might have.

The Chair (Mrs. Laura Albanese): We just have about a minute left in total. I don't know if there are brief comments that the members want to make; otherwise, I will leave it at that.

I want to thank you for appearing before the committee and for all the information that you've brought forward. This is very helpful to us. If we have any more questions, we'll be in contact.

Ms. Jasmin Earle: Thank you very much for your time. We really appreciate it.

DEOHAEKO SUPPORT NETWORK

The Chair (Mrs. Laura Albanese): Next, we will hear from Deohaeko Support Network. Good afternoon.

Ms. Helen Dionne: Good afternoon. We move a little slowly. A few of our members are coming up.

The Chair (Mrs. Laura Albanese): That's okay. Take the time that you need.

Ms. Helen Dionne: Thank you for this opportunity to come here today to present. I am Helen Dionne. I'm here to talk about Deohaeko Support Network. We're a group of families that came together 24 years ago to think about and plan good lives for our young adult sons and daughters who happened to have a developmental disability.

I'm the mother of Caroline, who has just passed her 51st birthday. She happens to be a photographer and a family historian. She loves to travel. She's a proud aunt, and she also is recently engaged to be married.

I'm joined here today by Linda. Linda is at the end of the table here, and Linda is the mother of Tiffany. Tiffany is an artist of some local repute, who is a member of the PineRidge Arts Council, a part of a studio art group and is active in the art world in many ways. She is also a member of the local drum circle, part of her church choir and an active member of her housing co-operative.

Barb Bosher here on my right is the sister-in-law to Brenda. Brenda is a good neighbour to the people in her co-op, for whom she bakes muffins for a surprise, and she offers gifts for birthdays and has potluck suppers. She's also a crafter, a puzzler and a great host in her home, as her mother was.

Mary Bennett, sitting here to my left, is the mother of Jonathan, who for many years had a small shredding business, J.B. Shredding. He's an active volunteer in his community.

I'm also joined to the left of me here by our coordinator who has been with us for 20 years, and her name is Janet Klees.

Twenty-four years ago, the families of Deohaeko began by thinking about where our sons and daughters would live in the future. What kind of a place would they come to call home and what might it look like? After much research and discussion, we had a good idea of the kind of welcoming, typical place we thought would work best. We took advantage at that time of the federal-provincial cost-sharing arrangement to design and build Rougemount Co-op in Pickering. Rougemount Co-op is a six-storey, 105-unit housing co-operative. Couples, singles, young families and elders of many cultures, abilities and backgrounds live together in a housing co-operative where they contribute to each other in many ways.

For our sons and daughters and for ourselves, Rougemount is not a residential option; it is home. It is where people are hosts in their own homes, co-operative members with rights and responsibilities and good neighbours

to one another. There is no support service within the building and no office for Deohaeko Support Network. Supporters work directly with people in their own homes, and our coordinator—we give her a telephone and a second bedroom in someone's home once in a while to use.

If Rougemount is all about where people have chosen to live, then Deohaeko, which is a separate incorporation—we had to incorporate to build Rougemount and then we had to incorporate to form Deohaeko Support Network—is all about the lives of our children. We're a group of families who come together to think about and plan for ways that our sons and daughters might live good, full and contributing lives at the heart of their co-operative and the larger community. After 24 years, we still manage to meet at least once a month, and talk together more often than that. We think about and we plan for supporting our sons and daughters to create a secure and welcoming home, to enter into a range of relationships with many people to keep them safe and to explore a range of typical and valued ways to contribute to their community as citizens.

We do all of this with a range of family support, assistance from our friends and neighbours and some consistent paid support. Our part-time coordinator works for us directly in a unique partnership that provides a layer of resources, support and resiliency to the voluntary efforts of the families. This feature of our group is vital to our sustainability.

1350

We're not a service model; we're not an agency. Board members are us, the family members. Paid supporters work for each family separately. Each person's life is very unique and is supported as an individual. Families help their sons and daughters hire their own supporters, plan their own schedules and remain in control of their own lives.

Our story is not about the co-operative, although this is a very nice place to live and all are welcome to visit. It is about people with disabilities leading good, ordinary lives at the heart of the community of their own choosing. It's about the capacity of families to be creative and innovative. We have a vision, and we follow it through. It's about intentionally developing community no matter where one lives.

At the same time, right now, we're standing at a crossroads. There's no doubt as to the success of our model, on a budget that's admirable, with plans for succession into the future. But as parents, we're all over 70, some in our 80s, and most of us are experiencing significant health problems. Two sets of our parents and our dear friends have passed on. Yet we remain at only about 60% of the funds required.

This means, as seniors, we are continuing to provide high levels of direct support, that supporters earn as little as \$13 an hour—I think our minimum wage is changing, so that's frightening—and that, after all this time, our financial future is not yet secure and we cannot move into

our own futures with any peace of mind. I also add that most of our fundraising days are over.

Our message today is that families need the resources and the flexibility to create and innovate. In this way, people will end up with a wide range of places to live within their communities in good ways. Let there be as many options as there are people.

I'll ask Janet to continue.

Ms. Janet Klees: I'm going to continue with some more of the details.

The seven families of Deohaeko Support Network are pioneers and forerunners in supporting their adult sons and daughters to live ordinary, meaningful and contributing lives at the heart of their community and from within homes of their own. We have put the theories of person-centred approaches into practice in Durham region for the past 20 years. For years, the government has been developing policy to move into person-directed practice and individualized planning and funding, lately in the social inclusion policy. We have long been putting these ideas into practice, well before that.

We have also pioneered other significant and complementary ideas: family government and support, a shared coordinator role to support families, community development, innovative social housing, supportive decision-making, customized employment strategies and social role valorization.

When we tell our many stories, we are not only talking about visions, hopes and dreams. We are talking about real lived experiences, achievements, goals met, and a good quality of life sustained over two decades.

Many families, organizations and others from around the world—Ireland, New Zealand, Australia, the United States and more—seek us out and find that our stories and lessons have resonance and truth. People buy our two books, visit us in Durham region, cite us as inspiration for their own models, invite us to speak across Canada and worldwide, and track us down to learn more. This is our track record.

At the start, when no housing was available for our family members, we researched, designed and built the Rougemount Co-operative with federal and provincial funding. When no service agency was even remotely able to provide support in the individualized way we imagined, we incorporated Deohaeko Support Network as a charitable not-for-profit organization so as to manage our own affairs.

When no support was offered at move-in time, families and friends moved in with sons and daughters until some of the support funding came about.

When our detailed individualized budgets and plans for each person 20 years ago were ignored, and instead we received just a chunk of funding, we invented group-based, flexible, individualized funding, which has allowed us to be innovators of this flexible nature of funding and allows us to share a part-time coordinator and to share our funds with each other in times of need, instead of each one just having their own.

When we wanted to ensure that our group had resiliency and flexibility, we designed a role for a shared coordinator. When the available support funding was only 60% of the original request in 1993, the families found ways to make it work, augmented by family support, supportive allies, fundraising and innovative measures. When the local supported employment programs five or six years ago deemed every single person within Deohaeko as unemployable, we went out and started our own customized job development initiative, and now five people are working at seven new paid jobs in our community. Furthermore, we've had enough time to reach out to six people outside of our group to provide the same service.

When all around us there were people with medical conditions and mental health conditions needing to use expensive and difficult emergency rooms, hospitals and in-house mental health services, we intentionally designed highly unique and personalized environments and support that have kept our fragile people safe and out of costly hospitalizations and systems. This includes three of our members who are very much medically fragile, and one has been assessed at the 95th percentile in the DSO SIS assessment system—just to show you the level of complexity we're talking about; not easy people to figure out support for. We designed ways that keep people with ongoing significant mental health issues at home versus in care during crisis—that affects three of our members—and other measures that keep people with very complex issues such as health, mental health, motherhood and social issues all safeguarded and on track.

When other families wanted to learn from Deohaeko, the group kept to their "small is beautiful" principle, and instead of expanding, we wrote two books and invited others to come and learn on study tours at Rougemount.

Finally, when parents began to think about the long-term future, when they would no longer be present, they got their wills and estates in order, put money into RDSPs and imagined friends of Deohaeko, which is the next generation of board members, and Barb would be one of those.

For over 20 years, this has been one innovative example of an effective family group. We have designed, tested, co-funded and constantly adapted to bring about a comprehensive way to support people with a wide-ranging and changing set of needs and gifts. For a time, about 10 years ago, MCSS seemed to recognize and appreciate our work, and we received a number of small funding project extensions to our funding in order to continue our work. However, political parties and systems change, and we have not regained that momentum. As has been pointed out, we have maintained all of this with only 50% to 60% of the funding that we require, and we are just not able to continue this for very much longer.

More clearly focused on this committee's mandate, we want to offer an idea of a good approach, and then, what is needed to sustain it. The question becomes: What will it take for governments to recognize, then support and

finally share good ways to help people live good, ordinary lives? First of all, we'd have to agree on what "good" means. "Good" is when people with a very diverse and sometimes complex set of support requirements are living unique lives of their own in the heart of their community in homes of their own where they are kings of their own castle, making decisions about their lives and support on a daily basis etc., in ways that bring richness to their lives and safeguard their lives. In other words, "good" is when people are living lives that are pretty well described in the social inclusion act of this government. Clearly, we agree on this.

"Good" is when a group of families show evidence of being able to sustain quality and stability for individuals over two decades. This is not a flash in the pan. "Good" is when the group is able to encompass people who require more complex supports and do it in a way that's very light on expensive emergency systems. "Good" is when families and other ordinary systems are excited and engaged enough to the point of proactively figuring out housing and creating new ways of support, new ways of employment etc. "Good" is when families are able to demonstrate economical ways of using government money that use innovation. Almost all of our funds go to direct support. "Good" is when there is demonstration of long-term sustainability and succession planned. As we say, we are into the future at this point.

1400

On all of these levels, we can agree that this is what is offered in this approach, and it's good—not perfect, but good. For individuals, it's good—for families, for communities and for governments elected by citizens in those communities.

The next point is, where does good make it sustainable? Support good efforts and effective projects in the following ways:

Where there is family innovation, energy and proven ability, including countless voluntary hours, the government should provide a way to ensure financial sustainability into the future.

Where there is long-term, hard evidence of people with significant disability being in charge of their lives, holding important contributing roles, finding places of belonging—evidence of people leading the lives outlined in the social inclusion act—the government should financially support the model and make efforts to learn from and share with the families.

Where there is evidence of personal and individualized support for over 20 years which keeps fragile and complex people safe, governments at all levels should recognize, coordinate and support these efforts with resources from several ministries.

Where there is evidence of a comparatively reasonable budget with good outcomes, governments should take notice of support for sustainability and learn from these examples, including reasonable compensation and cost-of-living increases.

Where there is a proven record of effective and affordable housing with good neighbourly relations, the government should learn why it works and offer more.

Where there is evidence of good job support that actually helps people get paid employment based on their interests, the government should find ways to fund this.

The need for an effective and comprehensive set of resources and supports funded by government in many creative ways to help support people with complex needs and dual diagnoses live good lives is clear. Our 20-plus-a-year example has been pieced and cobbled together and made comprehensive by the families. Why not fund it, study it, learn from it and share it? We are clear that our ways will not be suitable or interesting for all other families in Ontario. However, we know there is great interest among many for small, local family groups and individualized and personal community-anchored approaches such as this one. "Comprehensive" should not and will not mean that one size fits all.

As Helen said earlier, let there be as many options as people, and, we would now add, where it is working, make it sustainable.

Ms. Helen Dionne: I just wanted to add, these are our two books. *We Come Bearing Gifts* is the first book, and our second book is *Our Presence Has Roots*. Janet Klees is the authoress of our books. I'm sorry I couldn't bring 35. I can't afford it.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before our committee. There's less than a minute left for comments. But I do want to say, congratulations on such a successful model. It is something that we will definitely take into consideration. It is something that we've heard from other families: that they want to be involved and have more of a say. There are families who are willing to take on more responsibility, such as you have done. But you're right; you do need a partner. You need partners in this, and we will certainly take note of that as we consider our recommendations.

Thank you very much for your time.

Mr. Bas Balkissoon: Chair, can we find out how many clients they have and how many residents live in the co-op?

Ms. Janet Klees: There are seven sons and daughters of the founding families, and the co-op has 105 units and 225 people—just ordinary, typical kinds of people.

The Chair (Mrs. Laura Albanese): Thank you. That's very helpful.

Interjection: She just wants a copy—

Miss Monique Taylor: Yes, just to show us your project and how it works.

Ms. Helen Dionne: Yes, absolutely.

The Chair (Mrs. Laura Albanese): So you will be submitting the copy of the presentation—

Ms. Helen Dionne: We can, yes. We'll send it.

The Chair (Mrs. Laura Albanese): That's fine—in electronic form, and this way all members will get a copy. Thank you.

Ms. Elliott?

Mrs. Christine Elliott: While the next presenter is coming forward, I would just like to state, for the record, that I do have an association with the Abilities Centre. I'm one of the co-founders, and I'm currently the chair of the board of directors.

The Chair (Mrs. Laura Albanese): We'll take note. Thank you for disclosing that.

ABILITIES CENTRE

The Chair (Mrs. Laura Albanese): We now welcome the Abilities Centre. Good afternoon.

Mr. Leo Plue: Good afternoon.

Ms. Melissa Rudan: Good afternoon.

The Chair (Mrs. Laura Albanese): Welcome.

Mr. Leo Plue: Good afternoon, ladies and gentlemen. Thank you so much for the opportunity to present in front of this select committee. My name is Leo Plue. I'm the executive director of the Abilities Centre, and I'm accompanied by Melissa Rudan, who's our manager of programs and educational partnerships.

Abilities Centre is a state-of-the-art facility located in Whitby. It opened in June 2012 after many years of planning and building. The centre is open to the entire community, with special accommodations to meet the needs of anyone with accessibility issues, be they related to mobility, sight impairment, hearing impairment or any other issues.

The centre provides both self-directed and instructor-led programs in fitness, recreation, sports, performing arts, arts, life skills and music. We've established partnerships with:

- sports organizations such as Ontario Basketball, the Canadian Lacrosse Association, the Ontario Lacrosse Association, wheelchair lacrosse and Wheelchair Basketball Canada, as well as the para-sport organizations;

- cultural organizations such as Station Gallery, which is a local art gallery, the Royal Ontario Museum and the Royal Conservatory of Music;

- health care facilities: Lakeridge Health, Rouge Valley, Providence Healthcare and others; and

- many universities and colleges, primarily from Alberta and Ontario.

We deliver programs for all ages, all abilities and all activities, and believe strongly that it is more important to realize what an individual can do rather than what they cannot do.

The centre has been recognized with a variety of awards, locally, provincially, nationally and internationally. Our most recent award was for accessible design and was presented to us in Cologne, Germany by the International Paralympic Committee, represented by Sir Philip Craven, their president, along with its international architectural partner, known as IX. In August 2015, Abilities Centre will be the host site for two Paralympic events, boccia and judo.

While the built environment of Abilities Centre is unique and world-class, it is really the people and programs that make it come to life. Today, we want to talk

about two programs that are the focus of this select committee's work. To that end, I will turn it over to Melissa Rudan.

Ms. Melissa Rudan: Thank you. Good afternoon. My name is Melissa Rudan and I am the manager of programs and educational partnerships at Abilities Centre. I am excited to be here this afternoon to speak with you about some of the innovative programming we offer at Abilities Centre for adults with disabilities.

I'm proud to introduce you to Thrive, a signature program at Abilities Centre. Thrive is a fee-for-service adult day program that enables individuals with disabilities age 21 and over the opportunity to spend the day engaged in meaningful, integrated programming in the areas of sports and fitness, life skills, arts and social recreation. The focus of Thrive is to improve the health, well-being, community access and independence of participants through a variety of activities.

Thrive was created in response to feedback from adults in Durham region living with disabilities, as well as their parents and guardians, as part of a needs assessment conducted by Abilities Centre in the fall of 2012. An overwhelming 88% of those surveyed indicated that a quality day program was needed in the Durham area, especially one that was inclusive, accessible and included a variety of meaningful activities.

As you know, individuals with disabilities may remain in the secondary school system until they are 21. However, unless they are continuing on with post-secondary education or have obtained full-time employment, these individuals do not have many options for structured daytime activities in the community. Feedback from our needs assessment indicated that programs for adults with disabilities were few, and less than 18% of those surveyed had participated in existing programs due to barriers such as lack of accessibility and affordability, as well as inappropriate program content.

Using information gathered from this needs assessment, we designed a program model, and the pilot of Thrive was launched one year ago. Since then, we have continued to grow and expand the program, due to the overwhelming response from the community and the success of the program.

Thrive is currently offered three days per week in morning, afternoon or full-day sessions. Participants have the flexibility of registering for as many or as few sessions as fit their own personal schedule and interests. We have partnered with community agencies such as Participation House Durham and Whitby's Station Gallery, among others, to provide specialized instruction.

1410

The winter program of Thrive currently offers fitness classes, recreational sports, drama, dance, music therapy, visual arts, social media, healthy snacking, customer service and a variety of social-recreational activities.

We have also partnered with several colleges and universities to provide placement opportunities for students enrolled in relevant fields. We currently have students from social work, nursing, recreational sports and leisure,

and therapeutic recreation programs assisting in the facilitation of Thrive.

We are in the process of developing a partnership with local high schools to potentially use the Thrive program as a transition step for students with disabilities who are in their final year of secondary school.

We have seen many positive outcomes for participants of Thrive. For example, after completing the 12-week fall program of Thrive, one participant's physical health had improved so much that she was able to gradually stop taking a medication needed for muscle spasms. Another participant, previously very shy and quiet, gained so much confidence that she was able to obtain part-time employment in a restaurant. Another new Thrive member had never felt comfortable attending any program without a family member, but after only a few days of Thrive, wanted to stay in the program on his own. Not only did this do wonders for his own independence, but it provided his family members with some much-needed respite time. There are triumphs and accomplishments for our members every day, and these are just but a few that I've chosen to share with you.

So why has Thrive been so successful? One reason is that there is such an overwhelming need for this type of program in the community. I am continuously receiving telephone calls or visits from parents who tell me that their adult son or daughter with a disability has completed high school, and that their child just stays at home all day with nothing to do. They want, as any parent would, for their child to enjoy life, be engaged within the community and have their own circle of friends outside of the family.

Another reason this model has been successful is the flexible schedule, which allows participants to register for sessions that best fit their schedule and interests.

We have also created this program to be as affordable as possible in an effort to try to maximize the number of individuals in the community who can participate in Thrive.

I believe the most important contributing factor to Thrive's success is that it is truly a community effort. Our team is made up of Thrive participants, their families, our staff, volunteers, placement students, community agencies, specialized instructors from the community and members of Abilities Centre. A program has been created where participants feel that they truly belong and have a place within the community.

What does the future hold for Thrive? Well, since the pilot of Thrive launched one year ago in January, registration has tripled. The winter program of Thrive—which actually did begin this morning—with 60 available spots, is currently full, and we are in the process of immediately expanding the program to increase capacity. We will continue to grow and expand Thrive with feedback from all those involved, especially the participants and their families. Our goal is to eventually provide programming five days per week and offer even more activity options at different times throughout the day, so participants can customize their individual schedule.

The popularity of Thrive is a clear indicator that this type of program is long overdue and has a ready audience. With increased attention of the government towards accessible, inclusive programming, Thrive is a unique, well-designed program that has demonstrated success within the community.

The second program I'd like to speak to you about today is an initiative for adults with autism. This fee-for-service program has been named Achieve and is in the final stages of development. Achieve will ensure a secure and supportive environment for individuals with autism who require one-to-one, or sometimes two-to-one, support. This social-recreational program will provide specialized instruction in the area of life skills, arts, sports and recreation. Utilizing the Abilities Centre facilities and highly qualified staff trained by the Geneva Centre for Autism, participants will focus on improving health, well-being, community access and independence. To encourage self-determined behaviour, participants will be offered choice through flexible program options. Depending upon individual interest, specific activities may include group or individual fitness, dramatic arts, music appreciation with a registered music therapist, life skills and use of our sensory room, just to name a few.

The pilot of Achieve is scheduled to run for 12 weeks beginning in June, and will offer full-day activities from Monday to Friday. Provided with the appropriate level of support according to their individual needs, this pilot initiative will work alongside existing programs at Abilities Centre, such as inclusive group fitness classes or the Thrive adult day program. This is to ensure that each participant is provided with a spectrum of choice regarding the level of social interaction and inclusion. This pilot initiative will be partially supported by a grant from the Unity for Autism foundation and Magna International. We hope that it will be as successful as the Thrive program has proven to be.

Thank you for the opportunity to speak with you today. We welcome any questions that you may have.

The Chair (Mrs. Laura Albanese): Thank you for your presentation.

We have about three minutes per party for questions. It is Ms. Jones's turn.

Ms. Sylvia Jones: As you can imagine, based on who is sitting beside me, we know a little bit about Abilities Centre.

I did have one question. With your Achieve program that you're starting in June, is there an age parameter on that?

Ms. Melissa Rudan: It will be the same as the Thrive program, so for individuals 21 and up.

Ms. Sylvia Jones: Okay. You said that the Thrive program—you have 60 in-programs and you're trying to expand it now?

Ms. Melissa Rudan: We are, yes. The winter program is currently full, and I'm still receiving calls and interest from families who want to sign up for it, so we're looking at ways to immediately expand the program. We're fortunate at Abilities Centre that we have the

space and the capacity to do that. We're currently running the program at a break-even. We're covering our costs on the program to keep the fees as minimal as possible for the participants. So with that model, we have the opportunity to expand it.

Ms. Sylvia Jones: Are all of the participants you are currently serving or offering program to—would they all be individuals who live in family-home situations? Or would you have young adults who are in a group home? What's the breakdown?

Ms. Melissa Rudan: It does vary. I would say that 80% to 90% of the individuals do live with their families. But we do have some individuals who live in the group home settings. It's great for the families, as well, because some of the families are still working, so it provides opportunities for their son or daughter to have activities during the day. Some are aging parents, so this provides respite for them. But primarily, it's for the individuals themselves to be engaged in meaningful activities throughout the day.

Ms. Sylvia Jones: How far would individuals be coming for your program? You're obviously based in Whitby—but how far are people coming?

Ms. Melissa Rudan: I would say, on the east side of Whitby, we have individuals as far as Cobourg coming, and on the west side, from Pickering and everything in between.

Ms. Sylvia Jones: That's great. Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Thank you so much. It sounds amazing.

I just had some questions about your supporters. You don't have finances in here. In terms of the fees for families, is it completely self-funded by families? I see you do fundraising as well, and I was wondering what the breakdown is, generally speaking, between fundraising, corporate sponsors, or whoever is sponsoring you, and fee for service.

Ms. Melissa Rudan: In terms of the fee for service, the fee that we charge our members for Thrive—if you're currently a member of Abilities Centre, it's \$15 for a half-day and \$30 for a full-day program. If you're not a member of Abilities Centre, it's \$20 for a half day and \$40 for a full day.

We also offer, through Abilities Centre, a membership assistance program. Individuals in financial need can apply to that program and receive an Abilities Centre membership at a reduced rate. That is supported through sponsorships and through fundraising.

Ms. Cheri DiNovo: So it really is almost all generated by the funds that folk are paying.

Ms. Melissa Rudan: It is. We also try, though, giving the students from colleges and universities the placement opportunities, in terms of getting the support that way and minimizing our costs. So we do try to minimize our costs as much as possible so that we can keep the rates affordable for the participants.

Ms. Cheri DiNovo: Thank you very much, and thanks for the work you do.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much for your presentation. I had an opportunity to visit the Abilities Centre in Scarborough and was incredibly impressed by the work that they're doing within the community and their understanding of the needs. Clearly, you've identified this as a growing need and are responding creatively to meet that need.

I was wondering if you will be sharing your learnings with the network of Abilities Centre that you are in touch with.

Mr. Leo Plue: We probably have four to eight tours a week that will come through Abilities Centre looking at both the facility in terms of accessible design, but also our program offerings. We're wide open. Anybody who wants to come in and speak to us, we're prepared to do that. We're sharing whatever we can. We believe that we are there to provide services for our community individuals, but also for organizations in our community. That's why we've established so many different partnerships with so many different organizations. We work very closely with Variety Village from Scarborough and other organizations throughout the province.

Ms. Mitzie Hunter: Excellent. In terms of the employment outcomes, I noted that that was also the confidence, really, to do more. If you could talk a little bit about how those matching type of connections are made through this type of program.

Ms. Melissa Rudan: Each member is unique. Every day we have minor and major accomplishments that we see within our members. We try to keep the program as small as possible, so we have the quality, and then we can do the individualized programming. Different members have different goals, and when we keep the program small, we can really individualize a participant's goals and their needs, and work with them. Again, we have so many resources within the community that we really are well-equipped to try to meet those goals and needs of the participants.

Mr. Leo Plue: I would also direct you to the back of the handout sheet that we gave you that talks about the program. On the back of that page is a poem written by one of the Thrive participants. I think it captures very well the attitudinal changes that are taking place for people who are in that program.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for being with us today and for making us learn more about the Abilities Centre. We know that some members do know everything there is to know about it, but it's great that, as a committee, we learned to know more about who you are and what you do. Congratulations.

Mr. Leo Plue: Thank you.

Ms. Melissa Rudan: Thank you.

The Chair (Mrs. Laura Albanese): The next presenter, unfortunately, will not be able to make it, but the one right after that is almost here. I would suggest that we

have a short recess until 2:30, and we will then resume the committee.

The committee recessed from 1422 to 1430.

MR. RYAN WALKER

MS. SUE WALKER

The Chair (Mrs. Laura Albanese): The committee is back in session. We welcome Ryan Walker and Sue Walker. Good afternoon. You'll have up to 20 minutes for your presentation. If it should be any shorter, that will leave time for questions and comments by the members of the committee. You may start at any time.

Ms. Sue Walker: Okay.

Mr. Ryan Walker: Okay, great. As was said, my name is Ryan Walker. This is my mother, Susan Walker. We're both developmental service workers. We both actually work at the same workplace in Oakville.

A little bit about myself: I've been a developmental service worker for about seven years now. I grew up in the field my entire life, as you can see, with my mom being a DSW as well. I'm not the only developmental service worker she has raised. Also my older brother and my older sister are developmental service workers. I also have family members who work in the field: aunts, cousins. Many neighbours and friends actually work with us at our workplace.

I have personally worked in the field in respite care, residential care, vocational services. I've done treatment and assessment. I've run the whole gamut of the possible services provided in developmental services.

I've had seven years' experience. My mom has had about 32 years' experience. I guess you could say all the exact same things about her as I've just said about myself.

My mother has also been the developmental service sector chair for OPSEU for over 10 years, just coming down from that position recently, in the past year.

As you can see, our family is definitely well invested—we're pretty big stakeholders when it comes to developmental services, where the field's going and how the Ontario government is looking at it today.

Why we're basically here today is to share our experiences with what we see as the current crisis and the critical need for funding for developmental services. From a staff perspective, I can tell you, we definitely do not get into this job for the money. It's something most of us do definitely because we care. Unfortunately, it does seem that this mantra has been misunderstood recently, because developmental service workers have been poorly underpaid for far too long now.

As a result of low wages and increased part-time jobs, we are seeing a high rate of turnover, and staff juggling multiple jobs just to survive. What this translates into and means is a lack of continuity in the services that we provide, the services as workers for the people we support and for our communities.

Unfortunately, some of the words that come to my mind when I think of explaining developmental services today are "inadequate," "improper," "underfunded," "inaccessible" and maybe "nonexistent." For example, we have people with developmental disabilities being placed in psychiatric and long-term-care facilities. They are being placed there either just to get a placement or just to receive care. If I were to put this to a metaphor, it would be like going to your auto mechanic to file your taxes. It's just not right. You're not going to get any good work done with that, and it's not going to help the situation at all either.

I guess I can give it over to my mom now. She can tell you some more stories and experiences of what she's gone through in terms of the lack of funding in developmental services.

Ms. Sue Walker: It's true: I've worked in developmental services for over 32 years, and I've seen complete changes. Today I'm seeing things that they stopped years ago. Individuals are being moved into nursing homes again, where 20 years ago they were all moved out because that was not the proper placement for them, as they are not ill; they're just a little bit different.

The growing waiting list in developmental services in Ontario is just getting larger and larger due to the lack of funding. If you look at facilities across Ontario, they have all kinds of vacancies due to operation budgets being cut, government not giving money to fund these facilities. They've closed most of the government facilities across Ontario; they're in the middle of closing one now. They've basically increased the waiting list because the people that have already had a placement are now taking a second placement, taking away from the people that are waiting in the community. Aging parents are getting more frustrated because they don't have places to put their children.

In my time, I have seen kids abandoned. Their parents can no longer care for them. They're frustrated; they don't know what to do. So you have them in your facility for respite, and they just absolutely refuse to pick them up. Then, it's a mad scramble to find a placement. In my time, when the children were abandoned, they were placed either at the facility they were abandoned at or the CAS took over. Nowadays, they're going to homeless shelters—you hear about them in the paper all the time; you don't hear the results of where they're going.

But these parents cannot do it. We have to increase funding in this sector so that the critical waiting lists are cut. We have—I'm sure you've heard all kinds of numbers—over 20,000 in Ontario alone. To go into the area where I work, their waiting list—to talk about how many thousand are on that list just doesn't cut it. The problem is across Ontario, and we need to fix this problem for the parents and the waiting lists.

Mr. Ryan Walker: As my mom said, in our experiences—just us personally; I'm sure you've heard many stories at this committee as well—we've seen clients abandoned, we've seen families pushed to the limits and we've also witnessed this crisis continue to grow. As this

crisis continues to grow, the gap widens between the demand for and the supply of services for people with developmental disabilities and their family.

We could go through so many examples of what we've just said in terms of abandonment. We've seen it personally and we've also heard it, being so connected within the field of developmental services through our own personal union, and being sector chair of developmental services. We've had the stories come to us from all around, all over Ontario as well. So we know it's not just an experience that we're having with our workplace; it's also something that goes province-wide.

What we'd like to leave you with today is that there is an urgent need to address the crisis in developmental services, and to address that crisis, we need more services and more funding. As we know, our place in Ontario right now is that we can afford to care for the most vulnerable people in our society. Thank you.

The Chair (Mrs. Laura Albanese): Thank you for appearing before the committee today. We have about four minutes for each party, and I believe it's the NDP's turn. Miss Taylor.

Miss Monique Taylor: Thank you so much for being here today and for your presentation. It's very much appreciated. We need to hear perspectives of workers, and we've heard them from several areas. I know we've heard quite a few from CUPE, and now you're bringing an OPSEU perspective to it also. It's important to hear, and it's sad to hear that you've seen so many people abandoned. Do you have an approximate number of how many people just alone you've seen abandoned?

Mr. Ryan Walker: I know in my seven years, I've seen three people abandoned completely from their family, given up full custody, and those are personal experiences I've witnessed, yes.

Miss Monique Taylor: Do you know the background history of those families? Do you have an idea? Was it just because they could absolutely not get the services that they needed or were they getting the services and just not able to cut it?

Mr. Ryan Walker: The majority—any time where I've heard it, it's usually upon waiting for placement into group homes, so wait-lists. In certain circumstances, the clients are very young and maybe certain needs are not displayed by that person, so it kind of puts them at the bottom of the wait-list. Then, the perspective of some of those parents is, "My child will probably be an adult before I get them into a permanent placement." And then the other ones I've witnessed, again, are pure desperation. A lot of it goes back to families not knowing what to do or just not having the supports to do what they want to do for their child and what their child deserves at home.

1440

Unfortunately, sometimes, especially nowadays, the clientele who we're dealing with are a little bit different from back in the day. In terms of behavioural programming, we know what actually can and cannot work today with our clientele a lot of the time. A lot of the time it's

just that those supports aren't there for them in their home. In terms of getting into the community, the wait-list is the biggest barrier.

Miss Monique Taylor: So, are you working in residential facilities? Are you working in community homes?

Ms. Sue Walker: Yes. I don't work in a community home. I'm a vocational support worker.

Miss Monique Taylor: Okay.

Ms. Sue Walker: The facility runs the day program, but we do work out of the homes in there. Ryan does work in residential.

Some of the clients I have seen abandoned have been ones whose parents were receiving care, but it was all over the place. It wasn't in one area. One week they were here, two weeks they were here and three weeks they were here, not waiting for a permanent placement. So the stress was on the parents, because when an individual is moved and not knowing what's going on, they go home for a few days and they take it out on the families.

They just can't deal with it. When you have younger children at home and you have somebody who can potentially hurt your younger child, plus not knowing if they're ever going to get a placement, I think they've hit the wall. One parent I know, we talked to her and she just phoned and said, "I can't do it. I'm not coming to get him. I just cannot do it. You have to do what you have to do, because I can't do it."

Miss Monique Taylor: So sad.

Ms. Sue Walker: And then, any time you try to contact them, you don't hear from them until they know that their individual has a permanent placement. Then a lot of them can become involved again, but a lot won't, because they're scared that, if they do become involved back in their child's life, they're going to eventually wind up with them again.

Miss Monique Taylor: So they're just walking away and never coming back?

Ms. Sue Walker: Completely walking away—

Miss Monique Taylor: Out of fear.

Ms. Sue Walker: —and having absolutely nothing to do with them.

One individual parent called me, being also the president of the local in the sector, about how she could get her child into our facility, because we do have the supports in place. We're a facility that's really lucky that we offer a lot more than a community agency does, so they want to come to our facility, but we have a no-admittance policy. We only take special cases.

You feel sorry for the parents. I mean, I've sat and cried with parents—

Miss Monique Taylor: Oh, no doubt.

Ms. Sue Walker: —because they just don't know what to do.

Interjection.

The Chair (Mrs. Laura Albanese): One more—

Miss Monique Taylor: You work in a residential facility. I'm curious about if the people who live in the facility are getting day support programs, because we're hearing a lot of that too, that people who are living in

residential are not getting the priorities for the day programming. How are you finding your individuals?

Ms. Sue Walker: We get full—I'm a vocational support worker. All of the individuals who live at our facility have a full day program. Some run from 9 until 4; some run from—

Miss Monique Taylor: So you're not finding a problem with them not getting it?

Ms. Sue Walker: We have no problem whatsoever.

Mr. Ryan Walker: That being said, though, again, we understand that our workplace is a workplace that is well-funded. We do get the supports that we need as developmental service workers, but again, being so invested in the field, and we being so connected to developmental services, we understand that that's not the norm at other places.

Again, a lot of the barriers are the aggression of the clients; day programs won't accept them into their programming.

Miss Monique Taylor: Thank you. Thanks, Chair.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter?

Ms. Mitzie Hunter: So, your comment was that you're seeing some of the cycles of 20 years ago come back. I'm wondering if you could talk a little bit, with your tremendous experience base combined, about what you would see as an ideal model for us to aspire to, and any steps to get there.

Ms. Sue Walker: I think the first thing is that you do have to increase funding to open more community group homes and either give them a job or have a vocational or an activity. Nowadays, a lot of facilities are using the daily activities, which is a wonderful opportunity for clients, because they're doing what they want to do. They're out in the community, they're going swimming, they're on computers—they have laptops; there are special programs out there for them. Some of them are taking college courses at the community colleges.

That needs to be offered to everybody. It's a start. Start building on the day programs for them and a placement for them, because even the people—the parents who are at home, they have no day programs or a placement, so they're with them 24 hours a day. They don't have special needs allowance to pay for a worker to come in to give them respite for a couple of hours, or they don't come into a facility that offers respite because the waiting lists are so long. They're always on duty. I think you have to increase funding to offer supports for the people that need them.

Mr. Ryan Walker: Yes, there's no joke around what our top, number one priority would be, and it would be increased funding. To touch on that, we've seen recently a lot of the older institutions closing down, closing up shop. The clients that lived there still exist. They've gone to group homes and they've gone to other facilities. Our biggest worry, again, is facilities like ours getting closed like those. We're not in a time where clients with epilepsy were thought to be possessed by the devil. We understand a lot more in the field. There are much better-

educated workers. We would say to continue to fund those existing programs and to beef them up and strengthen their purpose instead of closing down programs and just shifting the need of those clients onto other programs.

Ms. Mitzie Hunter: Do you see the needs of the clients changing?

Mr. Ryan Walker: I've done treatment and respite, so I see a lot of the younger clientele as opposed to the vocational. It's definitely a much higher prevalence in autism. I've said it a couple of times, and the clientele is changing in terms of some—I guess you could say, risks or fears are elevated a little bit in terms of aggression. If you're a single parent and you live at home with your teenage child with autism and they are bigger than you and more violent—even if they're not bigger, nobody wants to have to physically hold down their 18-year-old child because they're trying to aggress towards them because they didn't get Cheerios. So it's definitely a higher prevalence in autism, and the clientele that we're dealing with are a little bit higher-functioning than we could say in the past 30 years. It's just a different style of working with the clients as well.

The Chair (Mrs. Laura Albanese): Ms. Elliott.

Ms. Christine Elliott: Thank you both very much for coming today and for sharing your expertise and experience in this field. Certainly a lot of the issues that you've raised are things that have been told to us by previous presenters. As a matter of fact, we had a presenter this afternoon who talked to us about the hidden number of people who need service. We heard the number of 12,000 people who are on lists right now, but I think you mentioned something like 20,000 people who are really needing service. Is that including that sort of so-called hidden population that aren't there now?

Ms. Sue Walker: Yes. With the research I've done, it's 23,000 across Ontario, and I think OASIS has the same number. That's what we've been able to come up with. I think they go to the resolution committees and they get the waiting list from each resolution committee and then they talk to parents and groups and everything, and that's how they come up with the terms of 23,000.

Mrs. Christine Elliott: Well, it's really frightening when you think that we're barely coping with what we have now. In fact, we're not coping. The system is in crisis, so we really need some urgent action on that, and certainly we are well aware of that on this committee.

If I could ask one question about the vocational work that you're doing: Are you finding that it's getting any easier to place people with prospective employers? Are they starting to get the message about the benefits of hiring people with disabilities or not?

Ms. Sue Walker: The community I live in is very good at hiring. In Oakville they're very good at hiring our people. Oakville has a wide range: Christian Horizons, Community Living Oakville and Central West. They're pretty good at hiring them in the communities, but it's in the smaller-paying jobs, like McDonald's restaurants, the guys are hidden in the back. They're not out front to be exposed.

I went to Orangeville, and I happened to stop into Home Hardware and there was a developmental services person running the cash register. You could definitely tell he was DS, and he was doing a fantastic job. He was out in the public, he was talking to us, plus he ran the cash register, and I wouldn't say he's as high-functioning as a client I have placed in back rooms.

Ms. Christine Elliott: It's great to hear.

Ms. Sue Walker: It seems that the little communities do more.

Ms. Christine Elliott: I think my colleague, who's from that area, has a question as well. Thank you.

1450

Ms. Sylvia Jones: I'm just glad you plugged Orangeville. Thank you. We'd like to think we're very inclusive.

I had one question that tied into the hiring. You mentioned that the community you work in, Oakville, has been doing a good job. What was the trigger? What unlocked that potential, that understanding between value and inclusiveness and participation?

Ms. Sue Walker: I can just talk from our experience. We go in and offer our clients to volunteer for a few hours. We start them at volunteering, and that's why they've progressed to a hired position. There's also a factory in Oakville that came out of Community Living Oakville, Best Pack, and you have to be DS to work there. It's amazing to see. I mean, they're foremen; they run that place—unbelievable.

Ms. Sylvia Jones: So the volunteering is really more about educating the employers.

Ms. Sue Walker: Yes, to find out that they can go in and they can do the job. They're not going to disrupt their business, because you're certainly not going to place somebody in there that would disrupt their business. We have placed people in community jobs that their parents said they could never do, it would never happen, and they've done wonderful jobs.

We also have the seeing—the blind, for the dogs, and they also will take some of our clients.

Mr. Ryan Walker: Yes, in Oakville, at our workplace, we're a big part of our community. It's kind of like a community centre in a sense, when you think about it. We open up our services for renting the pool, gym, other services like that. There are always areas. There's a daycare on grounds, other services which aren't directly tied to us—

Ms. Sue Walker: Brain injury.

Mr. Ryan Walker: —for brain injury services, so really kind of getting out there. In Oakville, everybody knows our workplace. It's been around for 30 years. The grounds have been there, obviously, a lot longer in terms of the history, with an air force base and that. The connection to the city is huge because of that, and the history with it. Unfortunately, that's what we don't want to see lost with workplaces like ours and other ones which we've recently seen get closed down in the past.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Thank you again for participating in the hearings today. We appreciate your testimony.

Mr. Ryan Walker: Great; thank you.

Ms. Sue Walker: Thank you.

MCSS PARTNERSHIP TABLE'S HOUSING STUDY GROUP

The Chair (Mrs. Laura Albanese): Now we'll call on the MCSS partnership table's Housing Study Group. Good afternoon.

If you could kindly start by stating your name and your title before you begin the presentation, we would appreciate it.

Ms. Margaret Spoelstra: I'm Margaret Spoelstra. I'm the executive director of Autism Ontario.

Mr. Ronald Pruessen: I'm Ron Pruessen. I'm the board member for Opportunities Mississauga, and I've also been involved with this Housing Study Group.

Mr. Gordon Kyle: I'm Gordon Kyle. I'm the director of policy at Community Living Ontario and a member of the housing group.

The Chair (Mrs. Laura Albanese): Thank you. You may begin any time you feel ready.

Ms. Margaret Spoelstra: Okay. Thank you so much for your time. We appreciate the opportunity to speak with the committee again and are grateful for the opportunity for you to also take a look at what was handed out to you, which is our report.

About a year ago, a group of us who are members of the MCSS partnership table felt that there was a need for us to become more specifically focused on one of the many needs that people with developmental disabilities in Ontario face. A small subcommittee said, "Okay, we'll do this," and a group of us together, representing organizations, volunteers and the ministry, said it would be important for us to focus on housing because there is a significant crisis. We don't even need to rehash the nature of that crisis or the numbers. It's all laid out in the report. But we felt it was also extremely important for us to say, "What could actually be done in a practical way?"

So we conducted a study, and we got ideas from people around the province—45 of them, actually, who responded in a very short period of time—who said there are some really practical things we can do that we've already started, that have been successful, but that could really use additional supports. Out of that, then, emerged further information in our study, and today, as you know, I'm here with three other representatives from this group. We represent 11 organizations supporting thousands of families and individuals with developmental disabilities in the province.

The other members of this committee are listed on page 6, and you can see who they are for yourself on your own time, but we're very proud to be representing them.

We're going to be brief in our presentation because you have the report and we really want to save as much time as possible for questions.

Mr. Gordon Kyle: You will notice that the subtitle of our document is *An Action Agenda to Address the Housing Crisis Confronting Ontario Adults with Developmental Disabilities*. We really want to focus your attention on the crisis that does exist. You just heard in the last presentation some good examples of the type of crisis that we see at the community level and the numbers of people who are waiting for support. We've identified that there are at least 12,000 people who are looking for residential support. To put that in a bit of context, right now, the ministry tells us they provide residential support for 16,000 people. It's taken us more than 50 years to develop those residential options, so the fact that we have 12,000 still waiting for some form of support means that we have to figure out some new and creative ways to address this issue. It really is time to get on board with this to figure out how we avoid the traumatic experience that far too many individuals and families are facing right now.

We've outlined in this document an action agenda which we want to talk to you about a little bit today, and we really see that this aligns very closely with the idea of a comprehensive plan that this committee is working to develop. So we're hoping very much that you'll see some close alignment with some of what we've proposed here today.

Mr. Ronald Pruessen: One of the emphases in the report is also captured in the title, as Gord has just mentioned. We really do put some strong emphasis on the notion of an action agenda. It is time to act at this point. We're talking, to some degree, to the choir here; you're obviously on the same page. This committee wouldn't exist if most of you didn't agree that it is indeed long past time to undertake this.

We do believe that this is going to be a long-term process. No one is imagining flipping a switch and having everything look good by the end of 2014. But as we put on page 13 in the report, we must begin, and the beginning must be energetic, and earnest as well.

One of the other emphases in the report is on partnerships. We don't believe, after extensive discussions both within the ministry's partnership table and within the Housing Study Group, that it is either practical or even smart to rely exclusively on the Ministry of Community and Social Services for solutions. It is too big a problem. It is too complicated a set of tasks confronting us, given the scale of the waiting list and given the nature of the problem, to some degree. Instead, what we are suggesting is that the government tap the creativity and the resources of other players, as well as the ministry and the government itself: families themselves, agencies, communities and the various organizations within communities, and the private sector as well—developers and tech companies and the financial institutions, for instance, as well as other government ministries beyond MCSS, and indeed other layers of government.

Ms. Margaret Spoelstra: So, as Ron talked about partnerships, we know that they are crucial, but they do not mean that government can play a minimal role. The Ontario provincial government, in particular, can make or break efforts to genuinely solve the current crisis. The action agenda outlined by the Housing Study Group highlights key steps that would provide the government leadership resources needed to energize partnerships and truly transform the environment within which adults with developmental disabilities and their families are struggling.

There are a few examples, and if you turn to page 16, you'll see our three-year action agenda overview. It looks like this page. This really is the heart of the document, so it's the Coles Notes for the reports. If you turn to that, we're going to focus for a few more moments yet on a couple of the items that we think are really wise steps to go forward.

1500

The first one is the creation of a capacity-building task force. We think that this group can be tasked with developing a framework for capacity-building projects.

We recommend that five—at a minimum—initiative projects should begin in 2014 to create opportunities across the spectrum, but paying particular attention to adults with developmental disabilities whose parents, parental caregivers, are over the age of 80, and also to create a baseline and scorecard measure for ongoing evaluation of progress and planning.

Mr. Gordon Kyle: Another recommendation within the action agenda is to deal with the role that government plays in carrying this out. As Ron pointed out, the response to this issue really will require bringing to the table all of the various players who can play a role, both in government and in the public.

Within government, however, we really want to emphasize that we don't see this as a responsibility of the Ministry of Community and Social Services exclusively, but there needs to be other ministries and other departments of the government brought to the table. So we're recommending that a process, a committee process, be struck to bring together the appropriate parts of government and to charge them with responding to these issues. These will obviously involve bodies such as the ministries of health, housing, education and the bodies responsible for senior citizens.

We also want to point to the focus—Margaret mentioned it just briefly here—about senior parents and as a mechanism for prioritizing where we make our investments early on. We want to identify the aging caregivers who are out there across the province right now. We've made recommendations for particular investments in the early stages of this for people who are living with parents who are over the age of 70 so we can address those needs before they turn into crisis.

Mr. Ronald Pruessen: Just to wrap up, prior to some questions that you may have, we believe that your committee, this committee, can play a special and significant role in turning around a tragic story—or thousands of

tragic stories, to put it more accurately. We hope you will be bold and demanding in your recommendations, knowing how great the need is for far-sighted leadership from the government, as well as other players, at this particular point, and knowing, as well, given the quantity and passion of the testimony you have heard over the weeks now passed, how many people are waiting for you to do the right thing and how many people are ready to work with you in going forward in the months and years ahead. If I could put it bluntly, we are ready to do our part if you do yours. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for this presentation. I will now turn it over to my colleagues. We have about three minutes each to respond and ask questions. Ms. Hunter?

Ms. Mitzie Hunter: Thank you for appearing again. I know that this was circulated on two separate occasions to the committee. I'm wondering about your recommendations where you've identified funding, specifically on your page 16. I'm just wondering: Are these funds that the committee will seek proposals for initiatives, and then grant? Is that what your vision is for that funding?

Mr. Ronald Pruessen: Yes, that there would be a consultative process, an interactive process, both for the initial capacity-building task force, and then, in year two and three, we talk about the creation of an opportunities fund with resources that proposals from various community organizations, agencies and the like can apply for. For us, that seems to be a way to be able to tap grassroots creativity here, I think.

Ms. Mitzie Hunter: And is it one-time?

Mr. Ronald Pruessen: No, it would be—I mean, in some cases, it would be one-time. I think what we would envision is that the capacity-building task force, or the ministry itself, by creating some sort of mechanism, would make decisions about the pilot projects and the various proposals that come forward to see if they're working, if they are delivering the results that were promised, and provide ongoing funding for those that are clearly making a difference as far as community, family and individual needs are concerned.

Ms. Mitzie Hunter: In the body of the report, you talk about how the needs vary, and that there need to be different housing types. Are you seeing, in terms of the spectrum of housing that's out there, any sort of best-fit model? Have you seen that?

Ms. Margaret Spoelstra: I can begin to speak, and others can join in too. Really, it is so individualized. It isn't a matter of one size fits all. It's very much driven by an individualized process that keeps in mind the family's commitment to working through such a process.

There are actually a couple of points that speak to this—folks in the community who are on board, and other support mechanisms, but ones that really meet the needs of that individual. Particularly when they're adults, we have a better sense of what their needs are, and that needs to be conducted through a process that is related to that person.

Mr. Gordon Kyle: Yes, I would agree. I think that the important factor is the individualization of the plan that you put in place, to just sort out what exactly a person needs. In fact, we've traditionally had in the past an attitude that, if a person had very extensive support needs—perhaps some of the more intensive, traditional types of group living supports—that those are necessary for those.

I've seen some of the transcripts of this committee, and your committee has heard examples from groups around the province who have recognized that the more specific and intensive the need for support, the more individualized it needs to be. In fact, it often requires that the person have something developed that's very unique to them. So we really are looking at a range of options.

The Chair (Mrs. Laura Albanese): Ms. Jones?

Ms. Sylvia Jones: Thank you for your presentation. I obviously have not had a chance to read all of it. I very much appreciate the time you've put into the three-year action agenda.

I've got to tell you that saying that we're going to deal, in the first year, with caregivers over the age of 80 doesn't sound particularly bold to me. To me, that's as close to a crisis as you can get. But maybe you guys have all been in the sector, working so hard and talking to the government for so long, that that is bold. I don't know.

Mr. Ronald Pruessen: Everything is relative.

Ms. Sylvia Jones: That's very kind of you.

Mr. Ronald Pruessen: You're absolutely right. We've been experienced enough to know that there are hundreds of caregivers over the age of 80 who have been waiting, in some cases for 30 or more years, for the provision of such services. They don't have those yet.

We do, over a three-year period of time, certainly talk about all of the caregivers over the age of 70, at least those who've made it clear that they need these kinds of services.

But you feel free to recommend—

Ms. Sylvia Jones: Okay; point taken.

I'm sure you have been following and reading the presentations. We have had some pretty creative ideas and suggestions coming forward. I would be interested in learning from you whether there are governmental barriers that are standing in the way of some of those innovations, where we as a committee could say that even with this investment, we as a government are going to have to make some decisions—to your point that one size doesn't fit all—and open up the ideas and creativity to let some different models flow. Are you seeing that? Are you hearing that?

Mr. Gordon Kyle: There are several barriers to the kind of creativity and flexibility that I think is demanded here. I've heard of lots of issues with the Developmental Services Ontario, DSO, system. It's very much focused on identifying vacancies in existing services and placement. I would like to see, very much, that that system become much more flexible in identifying funding resources that are available to people, but not necessarily tying them to a bed that exists someplace in some community we might peg people into. This demands a lot

more flexibility and creativity than we've got within the system or we're able to do with existing resources now.

1510

Ms. Sylvia Jones: And the reality is that even with coordination of DSOs, you can look for vacancies all you want, but clearly there are not enough of them.

Mr. Gordon Kyle: No, that's clear.

Ms. Sylvia Jones: Okay.

Mr. Ronald Pruessen: Just a variation on that: I think one of the things we would like to see emerge in this capacity-building task force is exactly that ability to say, by bringing other players to the table and not just Queen's Park players, "This is a really interesting idea, and we need to put our money into this to try it out at least for a few years."

Ms. Sylvia Jones: Well, even today we had the Habitat for Humanity model, which to me makes a lot of sense.

Mr. Ronald Pruessen: Right. The extension of that, though, the flip side of the coin, is that at some point, whatever the flexibility and creativity about various models of service are concerned, there is a bottom-line component to this. The Habitat for Humanity example is an excellent one. Capital expenses as opposed to operating expenses is a key variable here. As wonderful as Habitat for Humanity's work will be in my home region of Peel, for instance, in the years ahead, they are not going to be able to provide the support staff for the people who will go to live in those houses. That is a crucial government role that needs to stay in place and be dramatically expanded.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: Yes, thank you. I'm going to start off where Ms. Jones left off. It sounds good. Is it happening?

Mr. Ronald Pruessen: Should we let silence speak?

Ms. Margaret Spoelstra: Not yet.

Mr. Ronald Pruessen: It isn't yet. We've had a meeting with the minister, who has been positive and encouraging but has made it clear in any number of cases that some of these steps are clearly going to await current budget deliberations. There is, I think, a clear commitment already expressed by the ministry and the minister to create the capacity-building task force. The key step for us is going to be: Will that capacity-building task force have some money to invest, as opposed to study?

Ms. Cheri DiNovo: As many parents have said, if you've read some of the witnesses, "No more task force. No more checking it out. We need help now." That's the crisis of the situation. Essentially, we're a year behind already on your action plan. That was the number one question.

Number two was that I was wondering if your committee had looked at some legislative shifts; for example, inclusionary zoning. It has been one of the Wellesley Institute's asks. It doesn't cost a dime but does require a change in the Planning Act so that, for example, municipalities that want it can require of developers that they set

aside certain numbers of housing units to be used for those with developmental disabilities or others, say in lieu of section 37 dollars in Toronto, for example, or something. It could look very, very different depending on the municipality, but it requires a legislative change at the provincial level. Did you look at those kinds of things as an option?

Mr. Gordon Kyle: Yes, we discussed various options that might be there, but the focus so far hasn't been that depth of analysis as to what those kinds of barriers are. We've really looked at the mechanisms we think would actually create movement to develop this. I really would expect that those recommendations will emerge from the groups that we've identified.

Mr. Ronald Pruessen: I think that capacity-building task force, for instance—we very much recommend that it include developers, municipal authorities and the like to help identify exactly those kinds of needs where the provincial government could be facilitated.

Ms. Cheri DiNovo: The reason I raise that is that it doesn't cost a dime, so it could happen now.

Mr. Ronald Pruessen: Exactly.

Ms. Cheri DiNovo: And in fact the same bill passed second reading already. It just never got to committee stage. So any help on that front would be very helpful, because there's no budgetary consideration but simply a Planning Act change.

Thank you very much.

The Chair (Mrs. Laura Albanese): Thank you very much, again, for presenting to the committee.

Ms. Mitzie Hunter: I just have a question for the researcher.

The Chair (Mrs. Laura Albanese): Yes, Ms. Hunter?

Ms. Mitzie Hunter: I wanted to see what the process is for vacancy management within this sector. If we could get some information on that, that would be great.

Ms. Karen Hindle: Sorry. Could you repeat that?

Ms. Mitzie Hunter: What is the process for vacancy management of the existing housing units?

The Chair (Mrs. Laura Albanese): Thank you.

MRS. ORLENA BROOMES

MR. JEFFERSON BROOMES

The Chair (Mrs. Laura Albanese): Now we'll hear from Orlena Broomes and Jefferson Broomes. Please come forward. Good afternoon, and welcome to our committee.

Mrs. Orlena Broomes: Good afternoon, and thank you for having us. As you heard, my name is Orlena Broomes, and I come as a parent of a son with developmental needs. Jefferson here is my son.

What we want to talk to you today about are the post-secondary needs of students with disabilities and also the employment needs of students with disabilities.

What I'm going to do, because I believe that to hear Jefferson's voice is more important than to hear my voice: I am going to go through quickly some of the

20 JANVIER 2014

situations that we've seen and some of the recommendations, and Jefferson then can talk about some of his experiences. He might just butt in while I'm talking, and that's fine. Then, afterwards, the floor is open for questions.

I've started by giving a profile of Jefferson. I think that's important because we need to know who we're talking about when we're talking about youth. I keep saying "students" because he's been a student for so long. When we are talking about youth with developmental needs, we are not talking about an aggregate set of people. We are talking about individuals, individuals who have needs that are separate one from each other.

Jefferson comes to you as an individual. His developmental needs stem from the fact that he was born prematurely. He was 600 grams, 14 weeks early. It is amazing at that point in time how people applauded him, how people encouraged him, how people wanted to see him succeed.

That changed as he progressed out of the hospital and into school, but he persevered and overcame many challenges, and that's another story altogether. Four years ago, he entered the post-secondary program at Sault College, doing the CICE program, which is a community integrated cooperative program—I think I've got that correct; the "E" is missing somewhere in there—which is a supported program, very similar to what you would find in secondary school in terms of support, one of the few programs available to students with special needs.

Jefferson completed that program in heavy equipment/automotive because his passion is cars. If you got to know Jefferson, you would know that all he talks about are cars. When he was five years old, I took him to the library. He was a regular at the library, but what he wanted to do—he said to the librarian: "Can you give me the video of the Backstreet Boys? And what do you have in here on cars?" That has continued all through.

He wants to own his own business, and so after completing that heavy equipment, he went on to the CICE program at Durham College. He now holds a diploma. Sault offers a diploma and Durham offers a certificate.

I will let you go through at your leisure some of the strengths of Jefferson, because they're going to come out as we go through the presentation. But suffice to say, he's at the point now where he has left college and he's in the market for a job, and we have found that the barriers there are still fairly enormous.

Because Jefferson is one of the few people in a program who have actually attended post-secondary education, we thought it also fitting that we should talk about some of the barriers in post-secondary for students with disabilities.

1520

Jefferson, you can pop in whenever.

I've got a daughter as well; Anna-Maria is 17 months younger than Jefferson. She doesn't have any developmental needs; in fact, she's at the higher end of the spectrum and was identified as gifted. So I didn't have any child who fit what we term "normal."

Every year, high school students all over wait in March, looking for the mail. They're looking for acceptances to college or to university. Every year, graduate students all over this province—July approaches, and they are looking to enter the job market after completing university or college. Every year in almost every household, they start the excitement of moving on to a different milestone in their lives. The exception would be households with students with developmental needs. Those students finish high school, and then there's a block. Where do they go? If, like Jefferson, you happen to be moderately functioning, then it is even more difficult. You cannot go into a group home—you'd better not be going into a group home—because you are too high-functioning. You need to get into a program to contribute meaningfully to your life and to society, but where do you go?

We were fortunate that we found out about the CICE program. They're not well known. When Jefferson started in 2009, there were only three: Sault Ste. Marie, Lambton and Sarnia—and Durham was just opening a college. We live in Barrie. It meant that he had to travel. We decided on Sault Ste. Marie because it offered a diploma program and it offered him the flexibility of doing the automotive course with heavy equipment. Seven hours away from home—that is a hardship, even for kids without special needs, never mind kids with special needs who don't even like to go to camp.

For the academic year 2012-13, when I did rough research on what was available—they have now moved from three to seven colleges. It's still scattered, but now we've got one at Georgian College in Barrie, and Jefferson and his school, St. Joan of Arc, were very vocal in pushing for that. We've got Confederation College—and I have listed the others here.

What we also found in his time both at Sault Ste. Marie and Durham College—and he graduated from Durham in April of this year—was financial barriers. If you do not qualify for OSAP, you do not qualify for the disability grant. If you do not qualify for OSAP, you do not qualify for the \$10,000 grant that would help you to buy the equipment you need for special needs. It is no use saying, "Go to the accessibility department and use those," because these students need additional support that the accessibility departments in these colleges cannot supply.

We also found that the privacy laws—and this came out much more at Durham than at Sault College—create a barrier. These are students who have gone into the CICE program because they need support, yet the privacy laws—I know they are there for a reason, and I respect those laws, but they prevent the parents or caregivers from communicating with the college about the student. So when Jefferson, who lived at college and came home on the weekend, came home and I saw he had some notes on the table and I looked and I saw not one promissory note but two promissory notes for \$3,000, I just blew my top. I called the school, and what was I told? "I'm sorry, Mrs. Broomes. We can't discuss that with you."

We need some amendments to those laws, particularly where they impact on vulnerable students. Do you know what the school said to me? "If you go and you take out trusteeship for him, then we can talk to you." When I told Jefferson that, I wouldn't tell you what his reply was, but obviously he was quite capable of taking care of himself.

Quickly, coming out of college now, he's ready for work. He's got a \$7,000 student loan. That needs to be paid. He also needs—he was very excited about school. He left St. Joan of Arc in a leadership position, organizing the ball hockey tournament there, which has been going on now for about eight years. He co-founded that. Rogers TV named him athlete of the week. He's got good salesmanship skills. He's a beautiful writer. I forgot to attach a letter he wrote to St. Joan of Arc teachers when he was leaving school. They cried. I cried, and I don't cry that much. But now he has got this, and his enthusiasm knows no bounds. He wants to go out there and be a contributing member to society, but what is he finding? Jefferson, what are you finding?

Mr. Jefferson Broomes: I can't get a job.

Mrs. Orlena Broomes: Now, his voice is low because he had a trach in and he had multiple surgeries.

The Chair (Mrs. Laura Albanese): Can you place the microphone closer? You can bring it forward towards you so that it's easier. There you go.

Mr. Jefferson Broomes: I can't find a job.

The Chair (Mrs. Laura Albanese): We can hear you now.

Mrs. Orlena Broomes: And some of the reasons for that being?

Mr. Jefferson Broomes: I'm either underqualified or they don't want to hire me for some reason or the other.

Mrs. Orlena Broomes: And part of the reason that employers don't want to hire students with disabilities, youth with disabilities, is because the stigma still exists out there. They don't know the capabilities. They underestimate the capabilities of these students. There's also a disconnect between post-secondary education for students with disabilities and the workplace. Even though you've got co-op placements, there's that disconnect in the wider workplace once they leave the safe environment of school. We need to educate employers about what these students are capable of doing.

Mr. Jefferson Broomes: I just think that if there was more education for employers, they'd be more likely to hire people like me. For example, I don't know if you guys watch the show *Undercover Boss* on TV. I think that's a great show, even though I don't really watch it. But I think companies should go undercover and see the policies and what they're doing to the company so they know more information about the company and they would educate their staff and people who work for them more.

I've applied to a couple of car dealerships in Barrie, some of the big-name car dealerships in Barrie. I brought in all my resumé's, and they don't even bother to even call me back.

1530

You look at some of these ads, and they say, "We'll train you. We'll train you. We'll train you." But I don't think they have enough training themselves to train people like me, or people in general.

My goal is to become a car salesman—well, it was; I don't know what it is now. But I look at some of those ads, and they say, "We'll train you," but you need an OMVIC licence, and they will train you. I apply for those jobs. They don't call me back. I don't think they even bother to look at my resumé.

Mrs. Orlena Broomes: I think, too, what has happened, because he is part of the Ontario Youth Employment Fund—he's part of that, and what we have found as well is that those employment consultants themselves underestimate what these students, what these youth can do. When Jefferson, from the time he's been registered—and they've got his resumé and they've heard his background, and you've seen that he's a leader. He likes writing; he writes beautifully. His car ads that he has done were part of the Summer Company—he got a grant from the Ontario government Summer Company and he ran his own company. But yet the jobs that they offer him: "There's a cleaner needed here." "We need somebody to stock shelves there."

These students, these youth, are capable of more than being Walmart greeters. I said before: They are individuals. You cannot look at them as a collective. You cannot say that Walmart is really good for hiring special needs students—they are; Walmart is good for doing that. So are McDonald's, Tim Hortons—but we need to rise above the thinking that these young people are only good for menial jobs. We need to recognize what their capabilities are. We need to know that they want to contribute to the tax base. I need to know that somebody's going to be supplying me my CPP pension when I get old, and if we let these young people off the hook by not giving them the training and the employment that they need, we have less in that tax base, haven't we? They don't want to be taking. They will use what you give to them to build on that.

Mr. Jefferson Broomes: I think society today only sees us as entry-level jobs. They want to leave us at the entry-level jobs. I don't think they really want to take a chance on us.

Any questions?

The Chair (Mrs. Laura Albanese): Yes, there will be questions, I am sure. We're starting with Ms. Jones.

Ms. Sylvia Jones: Jefferson, very briefly, because I see my colleague would also like to ask you a question: You mentioned that employers need to be educated. So give your two-minute pitch on what employers need to know so that they understand that you're a great asset to them.

Mr. Jefferson Broomes: Can you explain what you mean, please?

Ms. Sylvia Jones: Yes, what would you like employers to know when they are interviewing you?

Mr. Jefferson Broomes: I'm a great salesman—a huge salesman. I had a fundraiser at my old school. We had to raise money for the end-of-the-year dance, and we had to sell chocolate bars. By myself, I sold almost \$800. But that's not really the point.

I think, towards my goal, I can sell cars. Give me a car; I can sell it. I've sold a car within eight hours, alone, by myself. I think, honestly, I know cars, so I could sell myself. I think that if people gave me a chance, I would be able to get a job. I think people—it's very hard for me to sell myself, because people don't give me the opportunities to sell myself. I find it hard to sell myself. So if I got a job, I could bring a lot to the table. I could wash cars; I can do all that stuff. I don't want to wash cars. But I think that I have a chance to do jobs more than—I want to be CEO, one day, of a company. I want to do this and that. But I'll never get there if people don't give me a chance.

The Chair (Mrs. Laura Albanese): Thank you. I have two minutes each. Miss Taylor?

Miss Monique Taylor: Thank you so much for being here with us today. I'm curious to know if you're involved in any organizations to help you find a job.

Mr. Jefferson Broomes: I've been in the Ontario disability program to help me find a job.

Miss Monique Taylor: But no other work-connect organizations?

Mr. Jefferson Broomes: No.

Miss Monique Taylor: So when you go to find a job, do you tell them, "You let me wash your cars"—I'm just saying—"and then I'll show you the job that I can do," and work your way up? Do you think maybe that's a possibility? You have to prove to them, right?

Mr. Jefferson Broomes: The biggest thing is that I don't even get to the interview process.

Miss Monique Taylor: This one is to your mom. Have you spoken with your MPP in your area to see if there are any organizations out there that are working with young people to help them find work experience?

Mrs. Orlena Broomes: I haven't spoken to the MPP, but that is something that perhaps we can do. What we have tried to do is exhaust all the connections that we've got, and we've gone into employment agencies—Northern Lights, inclusive employment, those agencies that are there to help people like Jefferson get jobs.

Now, we can say that the economy is going through a rough time, but it's always a rough time for these students. I take your point that, again, going to the MPP might be another area, but we've done extensive searches through the programs available on the website, going through the government's website—

Miss Monique Taylor: So you've been looking into the resources, and that's why I was pushing you towards the MPP—not that the MPP would be able to help him get a job, but to provide resources that possibly you might not have known about.

Mrs. Orlena Broomes: Right. We've gone through that—myself, and he's done some of that himself—

where we've gone through the paper and we've looked at resources.

Also, one of the things we have started thinking about would be going to conferences as well where they talk about employment for people with disabilities, and hoping there to learn more about what's going on.

Miss Monique Taylor: And that's something that we've been working on here, is transitions—

The Chair (Mrs. Laura Albanese): Sorry. I have to interrupt. I have to go to Ms. Hunter to continue.

Ms. Mitzie Hunter: Thank you, Madam Chair. Thank you, Mrs. Broomes, for all that you do on behalf of both of your children.

Jefferson, it's so nice to meet you. I think you've achieved an incredible amount in your life so far, and I have no doubt that you will continue to persist until you achieve your goals.

I do want to say that actually getting a first job for any young person is one of the most challenging things to do, but once you have your first job, you can build on that, and you don't know how far it's going to take you.

I am aware that Goodwill Employment Services has operations in Barrie. They do provide transitional employment programs for people with disabilities. I highly encourage you to get connected with your Goodwill locally in Barrie, specifically with a career plan of getting into one of the car dealerships so that you can eventually contribute to that local economy by selling those cars, because I am confident that you're going to be able to do that. Sometimes you have to work your way up to get to your ideal job. I know that that employment program is designed to create transitional employment opportunities for people with special needs and disabilities.

1540

There's also the youth employment fund, which Goodwill is part of, which is subsidizing employment placements for young people with disabilities up to the age of 29. They will pay for any accommodations that you need, as well as the wages and salaries for the employer—so it just reduces their risk while you're trialling work.

Mrs. Orlena Broomes: He's not part of that youth employment fund initiative.

The Chair (Mrs. Laura Albanese): Your MPP may be able to give you more information in regard to that, locally—what agencies would be involved.

Mrs. Orlena Broomes: We will do that.

The Chair (Mrs. Laura Albanese): Thank you so much for your presentation.

Mr. Jefferson Broomes: You're welcome.

The Chair (Mrs. Laura Albanese): Good luck.

Miss Monique Taylor: Write us a letter and let us know how well you did, okay?

The Chair (Mrs. Laura Albanese): Yes.

MS. JUDY PAKOZDY

The Chair (Mrs. Laura Albanese): Now we'll hear from Ms. Judy Pakozdy. Good afternoon.

Ms. Judy Pakozdy: Good afternoon.

The Chair (Mrs. Laura Albanese): Thank you for coming to Toronto on such short notice.

Ms. Judy Pakozdy: FASD is my life, and I will talk about it 24 hours a day.

The Chair (Mrs. Laura Albanese): You may start any time.

Ms. Judy Pakozdy: My name is Judy Pakozdy. I used to be a pediatric nurse and a nurse manager for 33 years. Then, I was the executive director of the Fetal Alcohol Syndrome Society Yukon for 12 years and the inclusion coordinator for the Yukon Association for Community Living. And now, since I retired to Ontario, I'm an FASD consultant and advocate and co-facilitator of the Halton FASD parent support group. But my primary role in life is being the mother of a very successful young man living with FASD.

I've given Trevor the photographs of a bunch of the kids from our parent support group, because I want you to know that when you look at these kids, you do not see disability, and for them, that's a disaster.

You've had lots of presentations about FASD—I've been following the news—and certainly you got all the info you need, so I'm hoping that you'll be able to incorporate that information into decisions that you're possibly going to make.

As a pediatric nurse, I know that this disability is one of the most difficult for the children, youth and adults who live with it, because they look so normal and sometimes can act normal, so people think they should be normal all the time, and they can't. The prenatal brain damage that they live with is so devastating that it destroys every opportunity that they have for success as individuals.

The hope lies in providing appropriate supports, and those supports have to be family-driven, because no matter how many of these kids go through the foster care system—and I've seen many of them over the last 40 years—they all eventually go back to their families. Whether those families are good families or families who are still struggling or families who finally become sober and can take something on, nobody can take on a kid with FASD without supports. Love is definitely not enough, and sometimes love hurts them.

I want to tell you about my son Matthew. My son Matthew is the shining star in the photograph who looks like a hip hop dance teacher, because that's what he is. He's 34. He was adopted from Yellowknife when he was one. I knew he had FAS when I adopted him—but of course, I was a pediatric nurse; I could fix this. We've all learned over the last 33 years that I can't fix it, but I sure can make it a lot better life for him than the lives that he sees around him from all his friends and classmates. He presently lives in BC with a full-time caregiver. We receive individualized funding from the BC government, managed by a small non-profit group that I formed that's comprised only of people who love him and people who recognize that he is disabled. If they don't want to face the disability, we don't want them around. We don't want

to try harder anymore, because trying harder is what kills the kids.

These kids live on the streets; they live in the jails. You all know them. You know the Ashley Smiths; you know the Sheppard boy who died in the bike and car accident. All those kids have FASDs, and they were not diagnosed appropriately, or if they were diagnosed, it was put on as a label in addition to multiple other diagnoses that they had. It was not seen as an overarching brain damage that affected everything that they do in their lives.

So Matthew receives a disability payment, equal to welfare, to pay his rent, but we also get from that small non-profit the equivalent amount of money from the BC government that they would pay for 31 hours of support a week. That's all he qualifies for—this severely disabled child. But 31 hours of government money is pretty good money, so with that money, we're able to hire four different support people to keep him alive, happy, having a good life and safe.

In BC, he's also allowed to make up to \$500 a month before they touch a cent of his disability money, which is a real bonus.

His caregiver—he has lived with her for 13 years. I found her in a locker room at the Queen Alexandra hospital. She keeps him safe and comfortable at home. They live in a two-bedroom townhouse. They share it. He lives with a commitment to call her every three hours when he's out and about, and if he doesn't, she calls the local police. She has already trained the police, so they know about his disability. She has trained the EMTs that service his area in Victoria, so they know, when he calls, what it's all about when they get there. These police find him wherever he is—in a nightclub, you name it. They find him and they just go up to him and say, "Phone Carey right now." And it's amazing how just that keeps him safe.

It's not that he has always been safe. Between the years of 25 and 30, he started using alcohol and drugs, introduced by his lovely little dance students, and he became suicidal. He tried to jump off a bridge once. He tried to—oh, he overdosed on all sorts of drugs and ended up on a ventilator for three days. But out of that we were able to convince the government to give us more money to increase his safety, so we could increase the supports he got. So that was a big benefit.

We also found that AA doesn't work, and everybody knows that AA doesn't work for people with FASD, because if you have to go back over your mistakes in life over and over and over, they persevere on that and they can't get past thinking about that again, so they never move forward. So my son found a group called LifeRing, which is organized through California and BC—you know, all those socks-with-sandals people. They do only forward planning for your life, and he loves it. He goes once a week. He just thrives in that environment, and it's a social activity for him, which is really hard to find for our kids who have brain damage and don't quite act socially appropriate a lot of the time.

He also has three part-time support workers who work six hours each. One coordinates his life, his work, his recreation and other activities. She works with his job managers to ensure understanding between him and others in relation to his tasks and responsibilities and how to deal with stressful situations at work. He works as the admin support, a person in an office for low-cost housing. He gets a lot of phone calls where people are really stressed. She goes in and works with him to try to figure out how to not take that stress home and worry about them not being able to pay the rent or buy their kids Christmas presents and all that kind of stuff that they tell him.

1550

Another one participates with him in shopping, cooking and relaxation classes. He goes to yoga, Zumba and exercise class. He's studying now to become a Zumba instructor. The other one helps him with money and time management, and to be on schedule. These kids really only need an executive assistant, as we all do in life. It works like a charm. You know, we don't need to be spending tons of money, and all sorts of professionals, and locking these kids up in group homes. We need to be treating them with respect and believing that they can succeed, because they sure can, but they're going to need that help all their lives—all their lives. Never take it away; you take it away, and they die.

All of his caregivers are committed to each other and to Matthew. He considers his caregivers to be his best friends. He has great difficulty with relationships and making friends, and these guys are his best friends. I tell the parents that come to my parent support group, "What you need to do—it sounds awful—is buy friends for your kids. Find the most responsible kid in their classroom, talk to them about FASD, introduce them to your child and ask them if they'd like to participate in a project for all of their school years in being this child's friend"—teaching other people about their disability, helping them to fit in more in social activities.

Parents get shocked when I say, "Buy friends," but you know, that's what we're buying here: We bought his best friends; they're his support workers. It's a great life for him. It's not isolated; it's not locked out of the community. It's not what I would have chosen, but it's a damn sight better than dying on the streets.

So I've worked in this field for the past 40 years. I thought I was retired, but it seems I'm not, so I'll be going on doing this work until I die. It's kind of boring being retired anyway.

So what I want to tell you about what Ontario's specific priorities should be—funded diagnostic teams. I've talked to five so-called diagnostic teams throughout Ontario. They're in all the books: "Here's our five teams." And you know what? They assess one or two people a month. When we're talking about a disability that affects 2% to 5% of school-aged children; we are not talking about one or two kids a month. Most of them do not provide training for the parents and support afterwards.

It's just, "Here you are. Here's your diagnosis. Good luck with that." It doesn't cut it.

The other thing they need is FASD navigators for families. I was listening to the last young man who presented. His family needs a navigator to get him into all of this stuff. I'm not saying we're supposed to baby people, but I'm saying we have to recognize they're different. We are all different, believe me. None of you are like me, and I'm not like you. We are all very different individuals. Children with FASD came into this world to teach all of us, and by God, they are, in dribs and drabs at the moment, but this is an opportunity for all of us to learn how to be nicer to each other and more tolerant.

I guess that's all I have to say. Look at my pictures and recognize how wonderful these kids are.

The Chair (Mrs. Laura Albanese): Thank you. We have a couple of minutes for each party. Sorry, I lost count here; I believe it is Ms. Taylor.

Miss Monique Taylor: Thank you so much for the work that you're doing, and for bringing your son's story to our table, to let us know how his life is working and what you had to do to make sure that he was living a fulfilling life. I think it's a great picture of what could be happening.

When I listen to these stories of people with FASD—I have to be honest—I'm still so confused as to what their life really looks like, hearing that they need supports every step of the way and yet people would think that they're "normal."

Ms. Judy Pakozdy: And they want to pass as normal, so they're not going to tell you.

Miss Monique Taylor: Yes. I know for myself that it's really hard to absorb. What do we do to make sure that we're keeping these people safe? I'm also hearing that it doesn't matter what we implement at young ages; it's not going to change as they grow older, and those supports need to be continuous.

The picture that you have painted with your son and the supports that are around him—how does he feel about those supports?

Ms. Judy Pakozdy: He's in charge of them. In the beginning, he phoned me one day and said, "Mom, Lisa is not working out." She's one of the caregivers. I asked, "What's the problem?" "Well, I phoned her because I needed someone to come to lunch with me, and she couldn't come. She was busy. We can't have that kind of support worker, who isn't available when I need them."

Miss Monique Taylor: Does he understand what his support workers are for?

Ms. Judy Pakozdy: They're there to keep him safe and to make his life happy.

Miss Monique Taylor: That's his understanding of it?

Ms. Judy Pakozdy: That's his understanding, and that's their understanding of it. It's amazing how wonderful they are.

Miss Monique Taylor: Does he realize that he has a disability?

Ms. Judy Pakozdy: Very much so. He speaks at national and international conferences. In fact, he's pres-

enting in Vancouver, in April, at the national FAS conference. His topic is "Finally, I Am an Adult."

The Chair (Mrs. Laura Albanese): Sorry, I have to move it forward.

Miss Monique Taylor: Thank you very much.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: You mentioned the 31 hours per week—it's there; it's committed. I wondered if you could talk a little bit about having a society or community that is inclusive of people with disabilities. It's not about being hidden away; it's actually where it's an acceptable part of our everyday lives, whether at school, at work or in the community.

Ms. Judy Pakozdy: Matthew was bullied all through school. I didn't know that until he got older and told me that kids called him names. Matthew is also gay. He's aboriginal, he's gay and he's disabled—a triple threat, and he was seen as such by the kids at school.

Although I work a lot with disabled people of all disabilities, I rarely see total acceptance of the kids in school. My other son has a chromosomal abnormality. He's 21. It has been a 100 times easier to raise him, because he looks physically different and he's sweet. "Sweet" goes a long way. He was always in a separate classroom with the same five kids, all through school, right through high school, and now they're in the same day program. To me, that's inclusion, even though it doesn't look like it. He has real friends who he grew up with, who he knows and loves.

The Chair (Mrs. Laura Albanese): Ms. Elliott?

Mrs. Christine Elliott: Thank you very much for coming to speak with us about your experience and Matthew's experiences. I'm really interested in your views on the BC model and how you think it compares, relative to what Ontario is doing right now. Is that something that we should be taking a look at—to follow what they're doing there?

Ms. Judy Pakozdy: I didn't know that Ontario had a model for kids with FASD. Our kids here don't seem to fit into any programming until they break the law, and by then it's a lot too late—not too late in the long run, but it's too late for what should've been happening all along.

Without diagnosis, the kids get labelled as something else, so they often get serviced by the mental health groups, but it's not a mental health issue; it's an actual, physical brain damage. You can't fix that with medica-

tion or with counselling. Although Matthew does once a month go to a psychologist for counselling: "It's private, Mom." But he just goes so he can destress, and he probably could do the same thing with some yoga counsellor or something. It's just that he has connected with this woman, so he stuck with her.

But BC, Alberta and Manitoba have major commitments of funds specifically for FASD supports, and that's where the difference is. Ontario does not yet recognize FASD as a major disability, and it doesn't commit any kind of programming or funding supports to them.

Now, I don't think we need a whole bunch of programming per se, because most of what's out there can be modified for our kids, as long as there's somebody knowledgeable about the disability to work with the provider. But I think there needs to be—without diagnosis, we're all lost, and all these kids are lost. So the money has to go upfront into a diagnostic process.

In BC, they have 26 diagnostic areas, like LHINs, or whatever they're called here—health care provider groups—and each one of them has developed a diagnostic team that parents do not have to pay for. Here, parents have to pay for this. This is unbelievable, that if someone has a disability, they have to pay to find out about it.

Mrs. Christine Elliott: Thank you very much.

The Chair (Mrs. Laura Albanese): And thank you again for coming to speak to us and for sharing your experiences with us. We will definitely keep all your recommendations in consideration.

Ms. Judy Pakozdy: Thank you, and I'll be back.

The Chair (Mrs. Laura Albanese): This concludes our day.

Ms. Sylvia Jones: One quick question for research: Have we asked—and if we haven't, can we?—what the annualized funding is for the DSOs across Ontario? I know we've seen a few numbers in the packages, but I don't think we've seen anything from the ministry. Thanks.

Mr. Bas Balkissoon: One of the groups said \$1.4 billion.

Interjection.

The Chair (Mrs. Laura Albanese): We're adjourned until tomorrow morning at 9 a.m.

The committee adjourned at 1603.

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CONTENTS

Monday 20 January 2014

Developmental services strategy	DS-445
Developing and Nurturing Independence.....	DS-445
Mr. Rudy Barell	
Ms. Kathy Laszlo	
Ms. Laurie Watt	DS-448
Peel Planning Group	DS-452
Ms. Leanne Baldwin	
Rygiel Supports for Community Living.....	DS-455
Ms. Donna Marcaccio	
Halton Special Needs Family Network.....	DS-459
Mr. Nick Norvack	
Mr. Tom Mahoney	
Family Service Toronto.....	DS-462
Ms. Janet McCrimmon	
Ms. Patricia Parker	
Ms. Nicole Flynn.....	DS-465
Ms. Kathryn Primrose	
Ontario Agencies Supporting Individuals with Special Needs	DS-467
Ms. Jane Joris	
Mr. David Barber	
Mr. Allan Mills	
CUPE Ontario	DS-470
Mr. Fred Hahn	
Developmental Services Toronto Council	DS-473
Ms. Jasmin Earle	
Mr. John Mohler	
Deohaeko Support Network.....	DS-476
Ms. Helen Dionne	
Ms. Janet Klees	
Abilities Centre	DS-479
Mr. Leo Plue	
Ms. Melissa Rudan	
Mr. Ryan Walker; Ms. Sue Walker.....	DS-482
MCSS partnership table's Housing Study Group.....	DS-485
Ms. Margaret Spoelstra	
Mr. Ronald Pruessen	
Mr. Gordon Kyle	
Mrs. Orlena Broomes; Mr. Jefferson Broomes	DS-488
Ms. Judy Pakozdy	DS-491



DS-15

DS-15

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Mardi 21 janvier 2014

Select Committee on Developmental Services

Developmental services strategy

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Stratégie de services
aux personnes ayant
une déficience intellectuelle



Chair: Laura Albanese
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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON
DEVELOPMENTAL SERVICESCOMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Tuesday 21 January 2014

Mardi 21 janvier 2014

The committee met at 0901 in committee room 1.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good morning, everyone. I call the Select Committee on Developmental Services to order. It is the last day of public hearings here in Toronto before the interim report.

FAMILIES FOR A SECURE FUTURE

The Chair (Mrs. Laura Albanese): We will hear first this morning from Families for a Secure Future. Good morning.

Ms. Judith McGill: Good morning.

The Chair (Mrs. Laura Albanese): How are you? Thank you for making it down bright and early on this very cold morning.

Ms. Judith McGill: We sledded down.

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes for your presentation. If you could please start by identifying yourselves with name, last name and title, that would be appreciated. You may start.

Ms. Judith McGill: Hello. My name is Judith McGill. I am the executive director of Families for a Secure Future.

Ms. Maureen Emmons: My name is Maureen Emmons and I am the chair of Families for a Secure Future. I'm also a parent of a wonderful daughter who is 31 and lives at home with me.

Ms. Judith McGill: We'd like to begin by thanking and acknowledging Christine Elliott for her perseverance and determination in calling for this select committee. Our families are putting their faith in the ability of this three-party committee to make strident and coherent recommendations to MCSS that will better the lives of individuals who live with a developmental disability and their families. These hearings are incredibly timely for families across the province who feel disheartened by the transformation agenda.

In reading through the committee transcripts, we couldn't help but feel that many alarm bells have already been rung by other groups, representing many different constituents. André Marin himself, of the Ombudsman office, has been ringing alarm bells about the state of crisis that families find themselves in as caregivers, and he describes his investigation by saying that it is like a

leaking dam, and you're trying to hold back the rush of water. It can't hold water and there are plugs in the holes. Basically, the government has to go in and plug the hole as another one is pegged out of the wall and begins leaking.

He went on further to describe that the complaints coming into his office—more than 900 over a short period of time—were dealing with more complexity than his staff had ever met before and required more than a simple fix. The fact is that families today are in more crisis than ever before. Families need far more support than they're being given. There is also an ever-present worry about losing the support they already have. We are days, maybe weeks, from the filing of the Ombudsman report on the state of affairs for families. Families feel they've been heard and they feel that the complexity of their situation has been comprehended. Now, they wait to see if anything will be done.

As one of the oldest independent facilitation organizations across Ontario—we've been around now for over 13 years—we've learned a number of key things. Essentially, it is this: People need each other. They need to hold one another during difficult times, to celebrate with each other, to inspire one another, to help each other re-imagine their lives and imagine better, to problem-solve together, to pause and seriously listen to one another, and to have each other's back. If their lives are to transform and if they are to experience belonging in a sense that they are being seen as someone who contributes, they need others to be in their lives. They need others to believe in them.

Ms. Maureen Emmons: As an organization, I want to share with you a little bit about what we stand for. First of all, relationships are a significant safeguard for the future. People need support to participate and build relationships in their lives. We set out to build, over time, relational safeguards for both the individual and their family, safeguards with our facilitator who gets to know us over time, who gets to know my daughter and our children over time, and can support us in the way that we need to be supported and our children need to be supported.

We are committed to assisting individuals to build a supportive decision-making context in their lives where they are helped to make key decisions, those day-by-day decisions, so that people have more say in their lives

within the family context. That's a really important thing to support. We said from the beginning, when we were forming Families for a Secure Future, that the individual is the one who comes first and the family second, so we're always looking to what is best for the individual and with the individual.

We are committed to supporting individuals to re-imagine their lives and to rethink what is possible. We support individuals to hold a dream for their lives and make it known to others, so that it can happen.

We are committed to helping each other and helping each individual to develop their voice. We believe that everyone has a voice by indicating their preferences and their will. We assist the individual to find or develop their voice and, in so doing, begin to shape and direct their lives.

My daughter, Jessica, isn't able to speak very well. She has very few words. However, through time, we've been able to figure out and have other people figure out what it is that she likes, what she wants and what she wants to do, and we've been very successful in supporting her to be out in the community, to volunteer, to have her presence known and to make a difference in the lives of others. That wouldn't have happened without the facilitator, through time, figuring it all out with her support circle and others.

We are committed to doing whatever it takes for the individuals to become contributing members of their community and to take up their adult roles, and we are committed to building capacity. Our primary role is to help individuals and their families figure out what is the most pressing need at any one time and what their next step is in addressing that need.

We help families foster resilience and build capacity. We believe that personal transformation and change involve families, not just individuals.

Ms. Judith McGill: We believe there are significant concerns facing families at this time, not only ours but those whom we connect with and network with across the province. One is the response to crisis. Families are put under immense strain, emotionally and financially, to care for their sons and daughters, and these same families are often in the position of caring for frail parents as well. These strains increase the incidence of poor health among parents. Parental illness compounds the complexity of the caregiving situation.

Family respite services are inadequate in relation to the needs of families. Providing crisis respite beds cannot be the primary response to individuals and their families. When it's the only response, it is likely to only exacerbate the situation.

Being part of a family group helps to avert crisis. We have seven family groups across the province who come together on a regular monthly basis to have each other's back, to be there for one another over time and to provide mutual support. The intentionality matters. It offers emotional support as well as tangible help by expanding awareness of local resources and through collective problem-solving and co-inspiring one another. Having

access to planning and facilitation support also aids significantly to prevent family crisis. Families need to be consulted about how crisis is portrayed, imagined and resolved. We cannot expect regional crisis protocols to go anywhere far enough to reach what families need in order to understand how to get through a family crisis.

0910

Planning and facilitation must be linked to be effective. We can no longer have planning be the focus and facilitation be put to the side. Independent facilitation is equally about facilitation as it is about planning. They cannot be delinked. They are integral to good support.

Facilitators help create custom-fit supports, negotiate the service system and understand how to use resources that are allocated. When people are getting so few resources, there is a real need for facilitation support to make the most of what people have.

Another concern is that relationships, as Maureen has said, really are the only safeguard, and people need others in their life to assist with supported decision-making. We have for far too long accepted the best-interests argument for people; we've accepted guardianship and substitute decision-making. We now, with the UN declaration, understand that supported decision-making is the way that we all make decisions, and so we need others to be around us, to hear the voices of the most vulnerable people in our culture at this time and to help strengthen that voice and help people have some say-so and practice having some say-so in their lives. We call that supported decision-making. We want to know what this province is going to do to ensure and presume capacity when it comes to decision-making.

The other concern is that individualized residential options offer security over the long term. Families for a Secure Future knows this to be true. We've helped people design and custom fit individualized residential options that are good not only for the family having a sustainable model going forward but the individual actually becoming part of their community and being truly seen.

We need broader access to Passport funding and more investment in individualized options. We need core funding for independent facilitation and planning organizations across the province.

We want to end with this and try to explain to the committee how important it is and has been over the last 17 years in the province to have some examples of good practice in the province about what it takes to be alongside an individual within the context of their family to actually have both planning and facilitation support. We have substantive concerns, as you'll see in the report, about the need for this to be funded across the province.

As an organization, for the first eight years, from 2000, we had solid funding through our own efforts at fundraising. We suddenly lost our funding and have found since then that fee-for-service as a model, which we had to adopt in 2009, is a model that isn't sustainable organizationally for a number of reasons, which you can read in the report. It's not a reliable enough source of income to lead an organization, to maintain and retain

staff, and we ask that the province of Ontario, through MCSS, take seriously the need for this kind of support that's indicated in the social inclusion act to help organizations become able to offer this across the board without the burden of cost to families.

I think we'll end it at that. You can read in the report what we suggest in terms of that. We'll take questions.

The Chair (Mrs. Laura Albanese): Thank you very much for your presentation this morning. We have about two minutes for each party to ask questions. Mrs. Elliott.

Mrs. Christine Elliott: Thank you, Chair. Judith and Maureen, thank you very much for being here today and thank you for the great work that you're doing assisting families across the province.

I do have three quick questions for you. The first one is—and this is something that came up during the context of the Bill 77 discussions a few years ago about when the planning function should be started. It was suggested that you should do the planning with the individuals in the family before you do anything else, because a lot of people might choose independent funding or individualized funding, but they just don't know how to go about it. Has that been your experience and is that what you would recommend?

Ms. Judith McGill: Certainly, you don't know what you don't know, and families haven't been offered this before. We believe that it should be a real offer when people start considering their adult roles, which would be around 16, way before they leave high school, so that they can leave high school with confidence that they're going to have a life.

Mrs. Christine Elliott: You also talk about how important facilitation is as part of the whole process. We've heard a lot of people say that they would like to have the assistance of system navigators. Would you equate the two in terms of the general roles that they would be doing?

Ms. Judith McGill: We believe that system navigation belongs with independent facilitation, where it's unencumbered, with no conflict of interest, and that system navigation, sorting things through, sourcing resources is part of the facilitation role.

Ms. Maureen Emmons: But I don't feel that that's the major role. The major role is having someone standing by you, and when you're trying to figure things out for your son or daughter and with our sons or daughters, that they get to make those decisions, and if it doesn't work, we'll figure something else out. You can't just have a plan and you can't just know where to go. You need someone to help with hiring the right support workers and training the right support workers, who will stay then and do what it is that we need to do. That's one of the things that our facilitators do.

Mrs. Christine Elliott: Okay. The final one has to do with the concept of supported decision-making. We've heard a little bit about that and that it is important. Can you tell us how it actually works on the ground, how you support someone to be able to make their own decisions in this context?

Ms. Judith McGill: Well, we have a lot of our families supported through gathering people around intentionally and helping them start to discern how to understand the individual more comprehensively: how to understand when they're communicating "yes" reasonably, "no" reasonably; how they communicate their will, their preferences. We do that sometimes in a support circle, where people gather regularly and come to know his or her story and what his vision of the future is. Supported decision-making means beginning with the individual and taking direction from him as much as possible, helping somebody have some say—so over their lives and honouring that to the extent possible—so, being collaborative, having other people speak to the issue, but trying to help the individual more and more have control over their lives by expressing their desires.

Mrs. Christine Elliott: Thank you very much.

The Chair (Mrs. Laura Albanese): Miss Taylor.

Miss Monique Taylor: Good morning. Thanks so much for your presentation. Thank you for being here today. I'm sorry, where is it that you come from? Is it the Whitby-Oshawa area?

Ms. Judith McGill: We're provincial, and we have six family groups in Guelph, Wellington, in Brampton and in Pickering, Ajax, Whitby—

Ms. Maureen Emmons: And Oshawa.

Ms. Judith McGill: Oshawa, Durham region.

Miss Monique Taylor: So just in different pockets across the province. And you talked about a funding model and that you used to receive funding. How much was that funding? How much does it cost?

Ms. Maureen Emmons: When we had our funding from a private source, we were up to almost \$100,000 a year from a private source.

Miss Monique Taylor: To run all six models?

Ms. Maureen Emmons: Yes.

Miss Monique Taylor: And currently you're doing a fee-for-service, which is a cost of how much?

Ms. Judith McGill: We have a mixed funding base. We have some raised dollars to keep the office and my position available, at a minimum, and then support the family groups on a monthly basis. We do some fundraising, but the rest is fee-for-service.

Miss Monique Taylor: And I'm just curious on what your thoughts on the DSO are?

Ms. Judith McGill: Do you want me to answer that?

Ms. Maureen Emmons: Yes.

Miss Monique Taylor: Be honest.

0920

Ms. Judith McGill: I think when Christine asked the question about who should be doing systems navigation, I'm not certain that it belongs there. They're a resource, but I think that the systems navigation belongs outside of that. In the Bill 77 hearings, we talked about the separation of some of the functions, and we feel that the DSO has now doubled up on many of the functions, where "an assessor is a systems navigator and is a this," and we're concerned about the redundancies, the expense of the DSO. All the things that contribute to making it a one-

stop place make it more difficult for families to actually have some autonomy.

The Chair (Mrs. Laura Albanese): Thank you.

Miss Monique Taylor: Thank you very much.

The Chair (Mrs. Laura Albanese): Ms. Hunter?

Ms. Mitzie Hunter: I just have one question, and then I'll pass it over to my colleague Mr. Balkissoon. I wondered about what you were seeing in terms of any changes in adults with developmental disabilities and what services they're asking for.

Ms. Judith McGill: One of the problems that we have with the DSO is that we feel that there's a bias in what happens when they go into an assessment, and that is that many, many families would say that they would prefer independent facilitation. Our families are finding that it's not being offered right at the point of contact during the assessment, during the intake, during that initial part of the assessment. Families say that they're not being asked if they would like individualized residential options, and we know that those two things are available and should be spoken to and addressed—

Interruption.

Ms. Judith McGill: —our 20 minutes is up, I guess—and yet it hasn't been offered. So we're concerned about there being an inherent bias. In families whose sons and daughters have led inclusive lives until they leave school, they get into the process and find that the options that they're being offered are agency-based options, so they don't have the support or even think that it's an option to think outside of the box. That, for us, is a real problem.

The Chair (Mrs. Laura Albanese): As you heard, the time has expired, but if you need to ask a question—

Mr. Bas Balkissoon: No, it's okay.

The Chair (Mrs. Laura Albanese): Okay.

Thank you very much, then, for your presentation this morning and for your recommendations. The committee will keep those in due consideration. Thank you so much.

Ms. Maureen Emmons: Thank you.

Ms. Judith McGill: Thank you.

ADULT PROTECTIVE SERVICE ASSOCIATION OF ONTARIO

The Chair (Mrs. Laura Albanese): We have a slight change in our agenda. We will hear from presenter number three before we hear from number two, because they're setting up for a PowerPoint presentation. Therefore, we call up the Adult Protective Service Association of Ontario, APSAO.

Ms. Dasha Choitova: Hi. How are you today?

The Chair (Mrs. Laura Albanese): Good morning.

Ms. Dasha Choitova: I'm just going to grab a glass of water first, before we start.

The Chair (Mrs. Laura Albanese): Sure. Please go ahead. Grab a glass of water. Make yourself comfortable. You may start whenever you're ready. The presentation is 20 minutes at the longest, and if it's any shorter, that will give us time for questions.

Ms. Dasha Choitova: Excellent; excellent. First I want to start off by saying thank you for having us here. It's quite a treat to be in front of you and to let you know a little bit about who the adult protective service workers are, what we do and some of the pressures that we're facing right now.

To tell you a little bit about us: The program started in Hamilton in 1974, and the goal was to support adults with developmental disabilities who live independently in the community and who have no family or other significant supports.

Over the last 40 years, adult protective services have provided support and guidance to these adults who live independently. We advocate on behalf of the people with developmental disabilities to help them manage their day-to-day lives and their personal issues.

There are approximately 165 adult protective service workers across the province, and we serve over 6,000 people. Some APSW programs are funded by ministry-run organizations, while others are funded as transfer payments to agencies. Some examples are given in my written report.

To tell you a little bit about the client, the adult protective service workers work directly to support adults with a developmental disability who are living on their own in the community. The workers assist them in strengthening their capacity to manage and acquire the skills necessary for daily living, and to help them enhance their community supports, as well as access generic-based supports and government-funded supports and services. In many cases, our clients also have co-existing mental health disorders, although they're not always diagnosed formally. These individuals are the most vulnerable in the community.

A perfect example that comes to mind is door-to-door salespeople. They're friendly, they're engaging, but they often force our clients to sign on the dotted line, and without knowing it, the clients are taken advantage of. This is where they need the APSW's support and plain-language interpretation.

To access APSW programs, an individual must contact and register with their local DSO, Developmental Services Ontario.

To tell you about the worker and what we actually do, the adult protective service worker facilitates an individual's involvement primarily with generic community supports whenever possible, but also with government-funded programs such as ODSP, the Ontario Disability Support Program, and legal aid, just to name two. The adult protective service worker assists the person to develop a network of supports that will foster greater personal independence and social inclusion. With the consent and direction of the capable adult who has a developmental disability, the worker will provide assistance with planning and accessing these supports based upon individual strengths, needs and goals.

The relationship between the adult protective service worker and the client is strictly voluntary, which means that the person is not compelled to accept the services of

the adult protective service worker and is not mandated to take their advice. The adult protective service worker is expected to provide the services within their mandate to people with a developmental disability who seek their help. The adult protective service worker does not have guardianship or legal custodial authority over the individuals they support.

I'll tell you about some of the limitations that exist within the role of the adult protective service worker. Participation in the APSW program is strictly voluntary. The adult protective service worker cannot compel an unwilling or disinterested individual to accept the services of the program from the APSW. The adult protective service worker does not have a mandate to provide or compel compliance to treatment or other recommended support services. While the APSW can assist people in making healthy and safe decisions, ultimately the final decision belongs to the adult who has a developmental disability and who is capable of making such decisions.

Situations that require direct observation of an individual after medical treatment or care, assistance with medical treatment, enforced treatment or guidelines or orders, or other more intrusive or intensive means fall beyond the scope of what the APSW is mandated to provide. The adult protective service worker does not serve in a guardianship or power-of-attorney capacity for the individuals they support and does not make personal care or property decisions on the clients' behalf. In addition, the adult protective service worker cannot assume legal responsibility for the adult or supervise their children.

There are a number of issues that the APSW and the individuals we support face that are unique to the program. Vast regional differences and inter-ministerial co-operation tend to be the running themes in presenting critical issues.

The first point I'd like to talk about is the transition from education to employment. As youth prepare to leave the school system, they often want to pursue paid employment but are often not prepared to handle the day-to-day routines of the workplace. Their inability to successfully retain employment results in a lack of self-esteem and increased social isolation. As the ODSP becomes their only income and financial source, it places these individuals well below the poverty line.

There is a need for more specialized pre-employment training and education, and on-the-job training.

0930

The APS clients are concrete; they require first-hand experience in the culture of the workplace. Many young people simply do not know how to work. Their expectations of the workplace are unrealistic. Skills such as attendance, hygiene, peer relations and supervisory relationships are simply not there. The ODSP Employment Supports program, as it is now, is unsuccessful in preparing these individuals for the workplace. In the experience of the APSWs, there is also little incentive for employers to hire adults with developmental disabilities.

Another point I'd like to talk about is around the alleged, suspected and witnessed abuse-reporting in adult

protective services. As you may know, quality assurance measures were implemented in 2011 and are part of the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008. It talks about the rules that agencies and Developmental Services Ontario, or application entities, must follow.

Quality assurance measures are rules that help the agencies and local DSOs provide high quality of service and supports, and meet set standards. Organizations funded by the Ministry of Community and Social Services that provide services and supports to people with developmental disabilities are required to be in compliance with quality assurance measures.

The adult protective service program establishes a voluntary working relationship based upon mutual accountability between the adult who has a developmental disability and the adult protective service worker. Adults who have a developmental disability are active participants in all steps of the working relationship.

This relationship becomes strained when quality assurance measures mandating the reporting of alleged, suspected or witnessed abuse are applied. As adults who live independently in the community, the APSW clients have the right to self-determination, a right that is compromised when their adult protective service worker is obligated to report to the police without the client's consent. The rapport is deteriorated as trust between the client and the worker diminishes. In many cases, the adult protective service worker may be the only support person in that client's life.

In the experiences of the APSWs, when situations of abuse are reported to the police, not all police divisions across the province are successful at addressing the issue. Many times, an individual is contacted, the alleged abuser is interviewed and the case is then closed. The APSW client many times has no other choice but to return to the abusive situation, where the abuse then escalates. As the rapport with the adult protective service worker has been compromised, the client is likely to avoid the worker and less likely to report anything ever again.

Another issue is around inter-ministerial co-operation. Often, health care professionals—a doctor, a physician, a nurse or a personal support worker through a community care access centre—are the first people who will observe physical abuse in a client. When a situation of physical abuse is observed by the physician who is treating an individual with a developmental disability who lives independently in the community, that physician is not mandated to contact the police.

While the abuse-reporting mandate is quite relevant and applies well to residential and day programs where the clients may not have the capacity or voice to speak out about experiencing abuse, the APSW clients' right to self-determination is eroded by the workers' mandate to report.

I'd also like to talk about aging in the APSW population. APS clients face another set of unique challenges as they begin to age. For most clients, aging is accelerated

by a number of factors, from poor nutrition that results from living below the poverty line and lack of a healthy lifestyle to lifelong use of medications that are prescribed for mental health or physical health issues. These clients deteriorate and age a lot faster. As workers, a situation we often encounter is a mature adult of 50 to 60 years of age whose health is rapidly declining and who is in need of enhanced supports and services. These clients do not qualify for generic seniors' supports, as they do not meet the age requirement.

The APS aging clients' health is medically complex, and the requirements that are placed upon them by their physicians and health care professionals in many cases are elaborate and need support to follow through with. While local CCACs, community care access centres, may offer personal support worker assistance that becomes instrumental in the clients' lives, these supports are limited and in many cases fall short. Our rapidly aging clients require assistance with daily upkeep—personal care, activities of daily living, medication reminders and assistance. While their physical abilities decline, the APSW clients also heavily rely on the systems that are around them, and these systems become strained as a result of these complex needs.

As workers, we often hear, "He shouldn't be living on his own. He needs to go somewhere else." As workers, we often say, "There's nowhere for him to go." Wait-lists for group homes and other residential services will in most cases outlive the aging APSW client. While some regions offer creative solutions like youth wards in nursing homes, those spaces are very limited and they don't exist province-wide. What happens is that the APSW client is left to deteriorate on their own, with limited supports, or, worse than that, placed inappropriately into a long-term-care facility.

In closing, I'd like to say that adult protective service workers and their clients face a unique set of challenges as the program allows unique supports to these individuals so that they can remain independent in the community. The underlying intent of the program of the adult protective service worker is to work directly alongside individuals who have a developmental disability to develop a trusting and respectful working relationship in order for them to understand the person's strengths, needs and goals. This partnership needs to encourage active participation and self-determination on the part of the person who has a developmental disability in setting and working towards these goals.

Across the province, the DSOs and networks of specialized care are working together and beginning to work well to support these clients in accessing services when in crisis. The involvement of the adult protective service worker plays an advocacy role of speaking on behalf of the individual in their relationships with the community and the systems around them.

Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before our committee this morning. We do have about a minute and a half for each party to

make comments or a quick question. I will start with Ms. Taylor.

Miss Monique Taylor: Thank you for appearing before us today. Thank you for the work that you do. I have to say it's the first I've heard of it, but I'm learning every single day as I sit at this table.

I believe you said there were a number of clients that—

Ms. Dasha Choitova: Over 6,000 across the province.

Miss Monique Taylor: So in a day, how many clients would an individual worker serve?

Ms. Dasha Choitova: In a day or as a caseload?

Miss Monique Taylor: As a caseload.

Ms. Dasha Choitova: As a caseload, again, depending on what the needs of the individual are, it can be from 14 to 28 clients in a caseload. When we're going into, for example, the northern chapter, which is quite vast, the caseload increases because there are fewer workers and a greater number of clients. The 14 to 28, I would say, is in the Toronto region, because I'm from Toronto and I can speak quite well about that, but I know that, for example, in rural Ontario, a worker can juggle 40 clients.

Miss Monique Taylor: So—

The Chair (Mrs. Laura Albanese): Thank you. Sorry, I can't. Ms. Hunter.

Miss Monique Taylor: Sure.

Ms. Mitzie Hunter: Just in terms of the inter-ministerial co-operation, can you talk about what your workers are seeing that's needed there and where greater supports are required?

0940

Ms. Dasha Choitova: There are a number of gaps that we're noticing. Some of the ones that I presented were around the transition from the Ministry of Children and Youth Services to the Ministry of Community and Social Services, for example, around preparedness of the client. In plain language, I can say that when a client becomes an adult by the ministry's standards, they're not prepared. ODSP is not in place, assessments are not in place, IDs are not there and things like preparation for employment are not there.

Other inter-ministerial co-operation themes around that would be, again, in regard to abuse reporting. A physician is not mandated to report, but we are. That doesn't make sense to me, and that's just to name a few.

Ms. Mitzie Hunter: Okay.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Jones?

Ms. Sylvia Jones: Yes, thank you. You are new to us, because I am not familiar with your organization. I know we have a brief amount of time. I wonder if you could provide to the committee an overview of where your clients are and where you're operating within Ontario, because honestly, in Dufferin-Caledon? Never heard of you. I don't know if it's the case that there are no APSWs in my community or you're operating under the radar; something's going on.

Ms. Dasha Choitova: We're there.

Ms. Sylvia Jones: Okay.

Ms. Dasha Choitova: Oh, we're there. Part of the reason—sorry; I hope I'm not interrupting. Part of the reason that we're here is so that you guys do know about us.

Ms. Sylvia Jones: Okay. If you could provide to us where you are and specifically what you do—you've raised some of the stuff about how you don't attend doctors' appointments and what you don't do; I'd like to know what you do. Would these be primarily clients who are SIL—supported independent living?

Ms. Dasha Choitova: Yes.

Ms. Sylvia Jones: Okay. So, if you could provide that to us—

Ms. Dasha Choitova: Absolutely.

Ms. Sylvia Jones: I'd appreciate it. Thanks so much.

Ms. Dasha Choitova: Not a problem. Again, this is why I'm really grateful to be here on behalf of the association, so that you are aware of our presence. We are everywhere. We are in rural Ontario and we are in urban centres. We work in the community, and we work directly with the clients in terms of assisting the clients to achieve their goals.

A goal may be, "I want to keep my housing," and we're there to help them plan to take the steps to support the client, so that the client can achieve that goal. A goal may be, "I want to go swimming. I want to be able to attend my doctor's appointment, because I live in rural Ontario and I may need to fly to my doctor's appointment."

We work on reserves. There are a lot of interesting issues that come out of there, of course. Our main goal, as we state in the presentation, is to support and encourage the client to be independent, so that they can stay living in the community and they don't become SIL—supported independent living. These are clients who have a developmental disability but manage to live in the community because of APSW supports.

I hope that answers your question. I can speak volumes on this.

Ms. Sylvia Jones: Thank you.

The Chair (Mrs. Laura Albanese): Yes, thank you. The time is almost expired. I just wanted to specify: These are adults with developmental disabilities who live in the community without a family or a support network close by. Is that right?

Ms. Dasha Choitova: Yes, that's right. Some may very well have families, but the families may not be in a supportive role.

The Chair (Mrs. Laura Albanese): But they're not close. Okay.

Ms. Dasha Choitova: As you know, family relationships may not always be perfect. Families tend to often be burned out by caring for the child as the child becomes the adult. These are adults who want to be independent and who are very proud of being independent and living in the community, just as you and I are.

The Chair (Mrs. Laura Albanese): Thank you very much.

Ms. Dasha Choitova: Thanks so much for having us.

The Chair (Mrs. Laura Albanese): Please make sure to send that information, perhaps through the Clerk.

Ms. Dasha Choitova: Absolutely.

WOODVIEW MENTAL HEALTH AND AUTISM SERVICES

The Chair (Mrs. Laura Albanese): We'll now welcome the Woodview children's centre. Good morning.

Ms. Cindy I'Anson: Morning.

Ms. Robin Brennan: Good morning.

The Chair (Mrs. Laura Albanese): We understand that you have a PowerPoint presentation for us.

Ms. Cindy I'Anson: We do. We're hoping it's going to work.

The Chair (Mrs. Laura Albanese): Yes, of course. When technology is involved, it's always an issue.

Ms. Cindy I'Anson: Yes.

Thank you so much for having us. "Woodview children's centre" is a bit of a misnomer. We actually refer to ourselves as Woodview Mental Health and Autism Services. My name is Cindy I'Anson. I'm the executive director. Robin Brennan is with me, and she is our director of autism services.

We're going to talk today about the issue of eligibility for adults with autism spectrum disorder and the need for lifelong supports. We have a very brief PowerPoint, and then we have four brief video clips of some of the people we support that will give you a really good snapshot of what we're talking about.

Ms. Robin Brennan: I just wanted to start by explaining very briefly about our services. Woodview Mental Health and Autism Services serves over 2,000 children, youth and adults in the communities of Hamilton, Halton and Brant. Woodview, along with Kerry's Place, is one of the few specialized agencies that offers ASD-specific programs for adults in the province and across Canada. Of the 2,000 children, youth and adults we serve within our agency, over 300 of those are served yearly with ASD—including ABA, IBI, respite camps, transition at high school and our varied adult programs.

Woodview's autism program in Hamilton is very unique in the province. It was specifically designed with Dr. Peter Szatmari and originally funded for higher-functioning adults. It's a very well-regarded and highly sought-after program that once was able to serve people across the province as a provincial resource, and then only the Hamilton, Niagara, Brant regions, and now we're only able to serve people in Hamilton.

We regularly get inquiries from across the province and Canada about wanting to duplicate our model. We offer a range of services that is a seamless, cost-effective, community-based alternative for individuals and families.

Specifically, I'm now going to focus on our Hamilton autism programs because that's where most of our adult programs are based. We provide comprehensive and consistent specialized ASD services and supports across the lifespan—so beginning at age seven and through to adult-

hood, including the key transition times of transitioning to high school and transitioning to adulthood. In Hamilton specifically, we provide services to 67 adults and 70 children a year.

We're a community within the community. We have a unique system of support, which includes developing extensive peer networks, which we have found greatly decreases the incidence of mental health concerns over time, including depression.

We focus on skill-building and use ABA-based ASD supports extensively. We focus on the core deficit areas in ASD: social life skills, communication strategies and supports, executive functioning supports, problem-solving and emotional regulation.

Our ultimate goal is, and has always been, to prepare individuals for life as adults and to be able to be as independent as possible, which allows individuals to reach their potential, as should be every person's right in our great country.

Ms. Cindy P'Anson: I'm going to talk briefly about the need for lifelong supports and the issue of eligibility.

ASD, autism spectrum disorder, is a lifelong neurodevelopmental disability that does not end at the age of 18. Extensive supports are available during childhood, and that includes IBI, which is intensive behavioural intervention, and ABA, which is applied behavioural analysis. They also have access to speech and language services, respite and Special Services at Home.

It should be noted that in Halton region alone, which is one of the three areas that we serve, there is a wait-list for ABA services of over 300 children under the age of nine. What will happen to these children when they reach adulthood?

Children used to be able to seamlessly transition into our adult services—and that's certainly the strength of what we provide: a lifelong service delivery model. Now they are often ineligible for adult services, and it's because of their IQ. They're high-functioning adults who have an IQ over 70, which I'm sure you've heard by now.

Eligibility is determined at a time when extensive supports are in place, which is problematic. Mental health and behavioural concerns escalate when supports are removed. An adult at 25 with no supports presents significantly different than a youth at 18 with supports in place.

0950

The regulation in the act has criteria that is too narrow and discriminates against people with ASD based solely on their IQ. The severity of core communication, social and executive functioning deficits, which are inherent in ASD, as well as adaptive skills deficits, do not carry the same weight as IQ in determining eligibility.

Measurement tools do not reflect the unique profile of people with ASD, and an individual's functioning in the real world cannot be predicted by their performance on pen-and-paper tests in a controlled environment.

We're going to show you four very short video clips of individuals that we support that have either just

transitioned into adulthood or have been with us for a while. Hopefully this works.

Video presentation.

Ms. Robin Brennan: I'm just going to pause after each one.

The Chair (Mrs. Laura Albanese): We can't really hear it. Is the volume of your computer at max?

Ms. Robin Brennan: We did bring speakers because we weren't sure if—we might be able to put that in, if we've got some time.

I'll just speak briefly about this individual before, and maybe they can try to put the speakers in.

This is Ryan; Ryan is 20. He recently went through, at age 18, the eligibility criteria process through the DSO. He met two out of the three criteria required, but not IQ. He's presented with a full-scale IQ of 85, so above 70. He presented with a very scattered profile. His subtest ranged from below the first percentile to the 63rd percentile, which is very typical in autism.

The Chair (Mrs. Laura Albanese): Could you place the microphone close to your—the one that is in the back?

Ms. Robin Brennan: Sorry.

Miss Monique Taylor: Technology.

Ms. Robin Brennan: Yes.

So Ryan presents with quite a scattered profile. He ranges from the first percentile to the 63rd percentile. It's interesting to note that some of the higher scores that he got were in things like spelling, which really don't relate to successful functioning in everyday life.

It's also interesting to note with Ryan that during his two full childhood assessments that were done by different psychologists, they both strongly cautioned—due to such variation between his verbal and non-verbal domains—that his overall level of functioning needed to be interpreted with great caution. Unfortunately, when the assessment was done at age 18 through the DSO, those kinds of factors were not taken into account. All that was looked at was the final number of 85, and he was deemed ineligible.

Now his family has decided that they can't leave him without supports, so they have decided that they will pay a fee to keep him in a weekly social and life skills group so he can continue to develop and learn skills.

Video presentation.

Ms. Robin Brennan: So this is Michael. Michael severely struggles with social interaction, communication, and has extensive sensory needs. He has had significant involvement with the law. Michael is 39, so he has been grandfathered from the previous system. It's very interesting to note that Michael's IQ is 90, so he is considered to have an average IQ. If he was to go through the system today, he would not be eligible for developmental services.

Video presentation.

Ms. Robin Brennan: So that was John. John is 44 years old. He struggles with regulating his emotions. You can see him starting to get a bit upset towards the end. He perseverates on topics which upset him. His father is in a

nursing home and his mother passed away last year. John's IQ is considered to be near average, so he's in the high 80s. Again, John has been grandfathered, but today he wouldn't be eligible, so it is a question of where would he be.

Video presentation.

Ms. Robin Brennan: Okay, and that's Katie. This is our last clip. As you can see, Katie has really nice social skills. She keeps a record of her schedule and checks it in her memory. She has excellent life skills. Katie is in her early 20s and was one of the first individuals in our program who went through the eligibility procedure with the DSO. Katie's IQ is under 70, so she was deemed eligible. 1000

I think it's really important for you to see the faces, that a number on these IQ tests does not reflect accurately how individuals with ASD function and it doesn't reflect accurately the things that they struggle with and the challenges they struggle with every day.

Ms. Cindy l'Anson: Just in closing, we'd like to say that adults with ASD who used to be eligible for funded services are now not meeting eligibility criteria for the most part. Many parents are self-selecting out of the process, which makes the need seem less, and that is because they feel that there is really no point in going through what is quite an extensive process, because they keep hearing that people are being deemed ineligible.

We're saying, do the extensive supports needs really disappear at age 18? We think not. We have some good examples that they don't. Autism is clearly a lifelong neurodevelopmental disability, and individuals with ASD need services and supports throughout their lifespan.

What can be done? We think there needs to be serious consideration given to addressing the eligibility criteria under the new act for individuals with ASD. When the new act was proclaimed and the regulation came out, we were quite hopeful. It seemed that it would allow the people we support to be eligible for services, but it hasn't turned out to be that way.

Thank you.

The Chair (Mrs. Laura Albanese): And we want to thank you for your presentation to us this morning. Unfortunately, the time doesn't allow for any questions, but the presentation was quite insightful and thorough. Should we have any other questions, we will make sure to get them to you. But thank you very much.

Ms. Robin Brennan: Thank you.

Ms. Cindy l'Anson: Thank you.

OPPORTUNITIES MISSISSAUGA FOR 21 PLUS

The Chair (Mrs. Laura Albanese): I'll now call on Opportunities Mississauga for 21 plus. Please take a seat. You'll have up to 20 minutes for your presentation. Should it be any shorter than that, we'll allow questions and comments.

Mr. Ross MacHattie: Thank you. Good morning, ladies and gentlemen. Thank you very much for the opportunity to address the Select Committee on Developmental Services.

portunity to address the Select Committee on Developmental Services.

Ron Pruessen and myself, Ross MacHattie, are first and foremost parents. We're also active board members of Opportunities Mississauga for 21 plus, an organization representing 180 families in Mississauga. Each of those families has an adult or a young adult with developmental disabilities.

Ron has acted in many roles for our organization, including past chair, and he sits on many different committees representing us. As a matter of fact, you probably recognize Ron from yesterday, when he was presenting on the Housing Study Group for us. I, myself, sit on the DSO for the Central West Region's advisory committee.

We're pleased to be able to present you some written materials that provide you our essential mandate, some background material and a priority program for us at the moment called Step by Step. This is a creative program that's able to offer services to a dozen families for the cost associated normally with just four families.

Generally speaking, we are the people that you have been hearing about over the last several months of testimony from the agencies and the ministry. We are the people living with the problems 24/7, year after year, decade after decade. We are the ones feeling the frustration, experiencing the challenges and feeling the despair that's actually endangering mental and physical health for us.

Mr. Ronald Pruessen: I guess one of the things we wanted to point out is that although we are those people that Ross was mentioning, we are not people asking you, the government, to solve all of our problems, any more than we have asked you to solve those problems over the past 20 or 30 or 40 years. We are parents from families with a powerful sense of responsibility that we have demonstrated over 20, 30 and 40 years in the past, and we want to be involved in finding and developing solutions for the critical problems confronting Ontario adults with developmental disabilities. We do not, for a moment, want to turn over the keys to our children's lives to you. We want to work in and with our communities and our children to develop solutions.

We also want and need to work with you, the government. Government has responsibilities in modern life: health care and education, road construction and public transportation—an endless list, as you all know perfectly well. Government uses tax revenues to provide vital social services, public goods, especially, it seems to us, for those who are most vulnerable in our society: at-risk children, seniors and those with disabilities. It's on the latter front, I think, that the government has fallen down so badly in recent times with respect to those with developmental disabilities. Those of you serving on this committee deserve to be applauded for recognizing the record of tragic failure here and for devoting your recent efforts to developing recommendations designed to produce what you have called a comprehensive developmental services strategy.

For our part as concerned parents and leaders of a large grassroots family group, we want to share with you

our insights and recommendations. These emerge, by the way, from many years of round-the-clock, hands-on experience, far more than might be the case for many of those who have testified before you representing agencies and various public services. If you do even a minimal mathematic exercise for our particular group, for instance: We have 180 families. Even if you imagine just one parent in each of those families and take an average length of time in which we have worked with our children and on behalf of our children of 30 years—and in many cases, it's more than 30 years—you have, in our organization alone, in one community alone, more than 5,000 years of experience that we bring to the table. That's an important contribution available to you at this point.

Mr. Ross MacHattie: Our sense of priorities is embedded in this report, in the package that you have before you. The Step by Step program is, of course, not our only creative idea, but it is one concrete example that is able to express the principles and approaches that we hope you will be able to embody in your report.

Mr. Ronald Pruessen: A bit of background on this Step by Step proposal: We designed it originally in mind to create what we call a transitional respite and residential program as a creative and cost-effective response to the long-neglected needs of adults with developmental disabilities and their families. It was presented to the Ministry of Community and Social Services in 2011 with the endorsement of all of Mississauga's MPPs. As many of you all know, one of those MPPs is now Minister of Finance. I don't know why I thought to mention that.

We were not even given the courtesy of a meeting with the minister to discuss the proposal, much less the funding needed to make the initiative a reality. This is an example of the past experience that has generated the kind of frustration and despair and alienation and anger that you have been hearing about over the past months. Funded or not, however, we remain convinced that the Step by Step proposal would provide one example of the ways in which valuable services can be provided. We know, from many conversations around the province, that it is the kind of proposal that would be greeted enthusiastically by many other communities.

Mr. Ross MacHattie: One of the key principles of this proposal is the concept of partnership. We believe that this creative, transitional, respite residential program embodies the co-operation that's required between government, between agencies, between family-run groups, between the whole community at large.

1010

The Step by Step initiative starts off as a partnership between a parent community group and a seasoned service provider, but it can then extend into the community through faith-based organizations, service clubs, local businesses. The entire community is going to become part of the solution with this approach.

We certainly do not expect government to be able to do this on their own. It's not reasonable; it's not practical. It's really key to understand that all of these other

members of our community have a stake in the game here. They have interests. They have ideas. They have resources. We need to be able to leverage that to make sure their interests help enrich these programs we are trying to launch.

Mr. Ronald Pruessen: The community component of this partnership principle is especially important to us. There are social connection and relationship opportunities within our communities that can dramatically enrich the quality of life of adults with developmental disabilities. These opportunities have been inadequately tapped to date. Families can play a huge role in changing this, since they live and work in their communities, and we believe that they are anxious to do so if baseline supports for residential programs and opportunities are provided by government and agencies.

Those baseline supports are crucial. Our emphasis on partnerships and community is not intended to give the provincial government an excuse to say, "Ah, well. This crisis will be solved by the families who have been doing the heavy lifting for 12,000 people on the residential waiting lists for the past decades."

Families want to play a vital role in solving the crisis, but adequate government funding will be needed to enable those family efforts to fuel the creative forces and energies that are waiting to be utilized more effectively in communities across the province.

With this in mind, we urge you to recommend that the provincial government make a dramatic and immediate start on what will inevitably have to be a long-term effort to solve a long-term problem. As much as we might wish for an overnight solution, no one seriously expects that to happen. But a beginning must be made to prove sincerity and determination.

You heard about the Housing Study Group's action agenda yesterday, for instance—I remember it—and the kind of recommendation contained in that about immediate and ongoing funding increases seems to us, as a family group on the front lines, extremely important.

From our point of view, a minimum of \$10 million a year of new and then ongoing funding for residential supports and initiatives in each of the next five to 10 years would make a powerful difference in the lives of adults with developmental disabilities and their families if those funds went into genuine front-line services, as opposed to process investments involving revised forms of administration.

Mr. Ross MacHattie: This committee can make a powerful contribution by taking a leadership role and helping to make up for the years of provincial neglect that have been demonstrated. We hope that your recommendations will be able to incorporate the views that we are trying to emphasize in today's presentation, emphasizing the vital contributions of partnerships, of communities, of parent organizations, of individual parents.

As Ron said, new government investment is needed now, but it's also needed for the long term, to ensure that any great strides forward this committee is able to start are able to be sustained to provide the meaningful response that we're after.

You have an opportunity to lay the groundwork for a new era, where Ontarians can be proud, as opposed to embarrassed, about the way we've treated the most vulnerable people in our society. As a large, grassroots organization, we urge you to think boldly and caringly about the leadership role that you have to play. We hope that your recommendations will be informed by our experience and our willingness to work with you and other partners.

We thank you very much for your attention to this extraordinarily serious issue. We welcome any questions or comments you might have at this time.

The Chair (Mrs. Laura Albanese): Thank you for your presentation. We will have about two minutes per each party for questions. Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I'm particularly interested to know—because we have heard now from a number of families and organizations before this committee—in terms of best practices across Canada and beyond, looking at your Step by Step model, do you consider your program to be a best practice within this sector?

Mr. Ronald Pruessen: At this point, we would like it to be a best practice in the sector. I think what you have heard is almost surely enough to suggest that, in Ontario at least, this is hardly a unique province in that respect. In Ontario, at least, we have too few best practices. We wouldn't have these enormous waiting lists, particularly for residential services.

At the moment, we have a very limited menu of practices at all. We believe that this kind of proposal, thoroughly endorsed and welcomed by many other communities across the province, would actually expand the menu of best practices in a very valuable way.

Ms. Mitzie Hunter: How do you suggest that we scale this across Ontario? There are varying needs in urban centres and in rural communities, and we would have that responsibility to have that—

Mr. Ronald Pruessen: I think this particular proposal, actually, would be very adaptable to communities of many different sizes. Keep in mind that we wouldn't for a moment suggest that this is the all-purpose solution to this problem. We think it is an extremely valuable solution for large numbers of people, but lots of other kinds of programs and services are going to be necessary as well.

For us, the transitional component of this would be extremely important for many families who don't want to create a situation where their adult children are being thrown into the deep end of a pool in a crisis situation. This allows a gradual transition that will develop life skills as well as allow the individuals to get used to being away from their families 24/7 around the clock. I think it's very adaptable, but it would need to be part of a long list of alternative models or best practices that could be developed in the province.

Mr. Ross MacHattie: Maybe I can pick up on just a couple of points there. The concept of a menu for us to choose from—as I'm sure you're being very well

sensitized to—the issues that people have to deal with are grand in the breadth of the issues, and so there is no one particular solution that's going to help. That's point number one: We need many solutions to be able to draw from to meet the needs around the province.

The other aspect, I think, is that this is a relatively small scale we're talking about, addressing the needs of a dozen families. So it does scale quite nicely across the smaller communities around the province, I believe.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Elliott?

Mrs. Christine Elliott: Thank you. This is a really intriguing proposal because it covers off a lot of the issues that we're really grappling with: the issues of respite, the immediate needs of families to provide housing, and also, it really looks at the individual and what their needs are and how they can best be met—as you say, throwing somebody into the deep end and all of a sudden moving them into another location is very stressful. It's stressful for anybody. I really like the concept of that as well as working in partnership with communities, too.

We know that government can't be all things to all people, and I think we really need to look at how we can provide the most service for the most people, working in partnership with communities, with service clubs and so on, and letting them know what the needs are. I think there's a lack of awareness on the part of some people about what the needs are in this sector, so one of the things that we want to do is to be able to help, let people know about that, and I'm sure you're doing your best in your area as well.

Can you tell me if there has been any movement on this particular proposal for Step by Step since it was, I guess, rejected in 2009? Are you moving forward with it independently, are you still in contact with government, or where is the proposal now?

Mr. Ronald Pruessen: First of all, amen to everything you said to begin with.

We continue to have discussions with Christian Horizons, which is the agency partner for us at this point, and we continue to make efforts to communicate with the Central West Region office of the ministry at this point, and with the ministry itself—no positive response, as far as the needed funding is concerned, which is, hardly surprisingly, a continuing source of frustration since we do see it as a valuable opportunity.

1020

We were hoping, for instance, that the \$42 million of new funding that went into the MCSS budget last year would provide an envelope of resources for just these kinds of initiatives. It didn't. At this point, virtually nothing was done to meet the critical needs on the residential front, which strikes us as the most powerful need within the province at this point. Some of the easier things have been done; the hardest thing of all remains untouched at this point, and our proposal and the lack of response to it is one example of that.

The Chair (Mrs. Laura Albanese): Thank you.

Mr. Ross MacHattie: Our children have taught us great patience, and that's helped us work with this effort of trying to tease out some funding.

The Chair (Mrs. Laura Albanese): Miss Taylor.

Miss Monique Taylor: Thank you so much for the work that you're doing and for the initiatives that you're bringing forward, because you've definitely been creative, from what I've been able to try to understand of the concept of how it all works.

My understanding is that it's a transition kind of learning with respite. Is that correct? A respite home for a month and then two months in the family—is that what I'm—

Mr. Ronald Pruessen: Yes, exactly.

Mr. Ross MacHattie: That's precisely it.

Mr. Ronald Pruessen: So four months in the course of a year, but with two months at home each quarter as well. So it's respite, particularly for the family, that would delay, hopefully, the burnout crisis situations that you've all been hearing about that lead to things like abandonment—relinquishment of care cases, to use the formal terminology—but also allow the development of life skills and social experiences, so that at the end of a period of three or four or five years of this, the ways in which the individuals who have been going through that experience would be able to move into other kinds of programs might be very different from what was imagined. I think it's very easy for us to imagine, in some cases, for instance, that the opportunity for a supported independent living arrangement would become obvious; that wouldn't have seemed so at the beginning. Though it's also perfectly clear that in many cases, you'd still be talking about the need to move into a full-time, 24/7 kind of—

Miss Monique Taylor: So it's pretty much in the way of and working towards that scenario.

For the levels of care, what would this model be looking at? Would it be a moderate level of care, or a high critical level of care would be able to be facilitated? What would this model—

Mr. Ronald Pruessen: I think the discussions with Christian Horizons at this point have suggested that the way to begin would be with moderate to low-needs levels of care—moderate, in particular. With low levels of care, supported independent living options already exist. As you've probably heard, in any number of regions, the funds available for supported independent living arrangements go unspent at the end of the year. It's moving up the spectrum, across the spectrum toward higher needs. But to begin with, probably a moderate level of care, but there's no reason at all why this could not be adapted to higher levels of care as it got up and running.

The Chair (Mrs. Laura Albanese): We thank you for presenting to our committee and for enlightening us into your project. We now know more about it. Thank you so much.

Mr. Ross MacHattie: Thank you for the opportunity.

Mr. Ronald Pruessen: And sorry for any confusion that I may have caused with this sense of déjà vu. Your heads must be spinning a little at this point in the process.

Miss Monique Taylor: We've had a few of you who keep reoccurring.

Mr. Ronald Pruessen: I'm not the only one; good to know.

The Chair (Mrs. Laura Albanese): Thank you.

Mrs. Christine Elliott: Chair, if I could ask a question: We may already have requested this from research, I just can't recall, but could we find out what has happened to that \$42.5 million, \$43 million that was allocated in last year's budget to reduce the wait-list for housing—where that stands right now?

The Chair (Mrs. Laura Albanese): I believe we had asked the ministry for a breakdown, but I don't think we've received it yet.

Mrs. Christine Elliott: Thank you.

Mr. Bas Balkissoon: Chair?

The Chair (Mrs. Laura Albanese): Yes, Mr. Balkissoon?

Mr. Bas Balkissoon: I wonder if we could get some background also on the assessment process, when it was started and this 70 figure—what's the scientific research behind it, or is it just an arbitrary number?

Ms. Sylvia Jones: The 70 IQ?

Mr. Bas Balkissoon: Yes.

The Chair (Mrs. Laura Albanese): How it was determined and—

Mr. Bas Balkissoon: How did the ministry arrive at that cut-off?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Soo Wong: And you know what, Madam Chair? Why don't we look across provinces? What are the other provinces' cut-offs in terms of eligibility? Are they using IQ as one of their criteria?

The Chair (Mrs. Laura Albanese): Okay. Interesting question.

Ms. Cheri DiNovo: Madam Chair, since we're on the research topic, I was just wondering—there have been a number of questions asked of research; when will we be getting the responses to those?

Ms. Heather Webb: Well, we are doing them as they come in, so we're certainly dealing with them as soon as we can. In terms of waiting for responses from ministries, we are unfortunately in the hands of that ministry to provide that information.

Ms. Cheri DiNovo: This is something we need to know. If the ministries aren't forthcoming with the information, we need to know that. We need to know why we're not hearing, essentially, is what I'm asking.

The Chair (Mrs. Laura Albanese): Would we be able to get a quick list, let's say, of questions—

Mr. Bas Balkissoon: Maybe a list of what requests we made and the status.

The Chair (Mrs. Laura Albanese): Yes, of questions that we've asked and which ministries have responded and which ones have not. And if we could get a date so that we get a sense of if it's a question asked two days ago or a month ago. Thank you.

TORONTO DEVELOPMENTAL SERVICES
ALLIANCE

The Chair (Mrs. Laura Albanese): We'll now welcome Toronto Developmental Services Alliance. Good morning. Nice to see you, Robert.

Mr. Robert Morassutti: Yes, it's nice to see you.

The Chair (Mrs. Laura Albanese): I know you've been sitting in the back for a while, so you know you have up to 20 minutes for your presentation. Should that be any shorter, that will leave time for comments and questions. You may begin any time. Please state your name and title before you do so.

Mr. Colin Hamilton: My name is Colin Hamilton. I'm the executive director of Surex Community Services, which is a transfer payment agency with the Ministry of Community and Social Services here in Toronto.

Mr. Robert Morassutti: And I'm Robert Morassutti with Montage Support Services, another transfer payment agency here in Toronto. We tend to support individuals that have complex care needs in addition to their physical disability, developmental handicap, and we offer residential and day services for them.

Mr. Colin Hamilton: We're here today representing the Toronto Developmental Services Alliance. The alliance is brand new. Formerly, our name was MARC, which stood for Member Agency Representative Council. That was established in 1985. We have a long history in Toronto. The alliance currently includes about a little over 20 transfer payment agencies in the city of Toronto. We represent probably about 20% of the provincial budget in developmental services in Toronto.

We have a lot of experience in this area. The collaboration is one whereby agencies are coming together on a monthly basis to really discuss our issues and work together. We work closely with our regional office; we have a good working relationship with our regional office. We, as an alliance, also sit on the provincial network and the other provincial tables. We're here today to talk a little bit about what we see are some of the issues across Toronto and in the province, and also to make some recommendations to you.

Mr. Robert Morassutti: Thank you. We know that the committee has heard a lot of presentations, and we don't want to belabour a lot of the information because I'm sure you've had personal experiences shared with you, as well as overall presentations.

The alliance, as Colin mentioned, is a collective group of transfer payment organizations, and we came together and tried to narrow down our presentation to three main points.

The first point we wanted to look at is Developmental Services Ontario. We know that the committee has heard a number of presentations with respect to Developmental Services Ontario, but we want to add our voice. We understand that the DSOs are legislated, that they do have a regulated, legislated mandate, but given what the intentions of the DSOs were set out to achieve, we feel that it hasn't really assisted families and individuals with the opportunity to access services any more easily or any

more immediately. That's certainly a concern of ours, that we hear, as organizations, the frustrations of families in trying to access services and the obstacles that many of them encounter. So I certainly would recommend that there be some review of the DSOs as they currently exist.

1030

Secondly, another issue that I'm sure the committee has heard is that of children moving into adult services. Most families who have children with some disability are able to enjoy a number of inclusive and supportive services and programs in the community while their children are children. Unfortunately, when they reach the age of 18—in some cases 16—most families are really not prepared for what they encounter. We hear this over and over and over again.

Children's services, such as education or child welfare, are mandated services by the government. As such, there's a real wealth of services and resources and funding available for children. That all changes when someone turns 18. We always say in the adult sector that children's has them for 18 years; we have them for the rest of their lives. The funding that seems to go towards children's services is certainly not comparable to what we experience in the adult sector. Families are continuously being, I guess, shocked and surprised by the way they're led to a cliff, as many have said to me, and then pushed off the edge, because what they enjoyed with children's services is not there in adult services.

The third point we want to focus on is the concept of "most in need." The ministry has adopted a stance where, because it's not able to provide services in the same way that they may be provided under children's or mandated or entitled services, there is that concept or that approach of most in need. As transfer payment organizations, we spend a lot of time trying to meet a lot of the regulated requirements, reporting requirements. We tend to be spending, I guess, an inordinate amount of time in terms of the administration and maintenance of a lot of these requirements.

The government is very good at providing short-term crisis management, but when we look at long-term planning, long-term funding, there certainly is a little bit of a gap there. We don't have a good sense of the vision for the future: where we're going and how we're going to get there.

As I said, we spend a lot of time in administration. That includes things like the quality assurance regulations, risk assessments, policy directives from the ministry, health and safety directives from the province, fire safety regulations, mandatory training and quarterly reporting. This all cuts into the available resources—limited resources—that we have as organizations, non-profit groups, and takes away some of the energy from the program or service development that we could establish. Rather, we are spending a lot of time meeting those regulated and reporting requirements.

Finally, under "most in need," we also have the issue of labour costs. We're sure that each person around this table here understands that area. We're looking at things

like pay equity obligations, regulatory requirements under quality assurance measures. Now with the Regulated Health Professions Act, in our case especially, any kinds of activities for daily living will require added training from medical personnel.

As we continue to provide these supports, these services, it certainly impacts on our ability to provide quality support to the people we are there to serve. Stretching those scarce resources is really going to erode our capacity.

Mr. Colin Hamilton: We've also included some recommendations for you to consider in your deliberations.

The first recommendation we'd like to make is around a multi-year funding approach. As you probably are aware, agencies in our business are funded on a year-to-year basis. At the end of each year, we do a reconciliation with the province. If we've lost money during that year, that is our board's problem and our agency's problem. If we have an excess at the end of the year, that's returned back to the provincial government.

What we'd like to see is a three- to five-year type of planning process where, within that time frame, agencies and boards have more flexibility on a year-to-year basis in dealing with ongoing funding issues and expenses that happen, oftentimes completely out of our control. So that's one thing we'd like to suggest, that multi-year funding idea.

Secondly, we feel that it's important for the government to go back to its original principles, where every citizen is guaranteed their right to work, housing, income, food and shelter. The needs of all citizens, especially Ontario's most vulnerable, should drive society's approaches.

Lastly, hitting on Robert's last point around the co-ordination between ministries and regulatory bodies, we really feel that our ministry needs to take the lead in looking at working with other ministries around regulatory issues. One would certainly be the issue around modifying the proxy pay equity obligations that many of us face.

When proxy pay equity first came in, the comparator that we were expected to use by the legislation was hospitals, so we now have groups of our staff who are on target to eventually make \$35, \$40 or \$50 an hour. If you are not a proxy employer, the gap that is going to exist down the road is going to be enormous. We think it's a regulatory change that could help fix the issue for us and take some of the pressure off of us on an ongoing basis.

Again, the new regulations that are coming out regarding QAM, fire safety and the Regulated Health Professions Act—there's no funding that comes along with these, and again, those are added pressures on agencies to deal with those. We're dealing with them within the existing budgets that we have.

As you're well aware, I'm sure, 80% of our budgets go towards staffing. When we want to make cuts, it's fairly obvious where we need to make cuts, and that's in staffing. Although we continue to provide service, we're not continuing to provide service at the level that we

really should be. As I've said on occasion, how much lower can you go than one staff on shift? You really can't, but many of us are doing that.

Lastly, we feel that employers need legislated incentives to hire citizens with developmental handicaps in Ontario. That certainly would provide opportunities for many of our adults who have those capabilities and abilities to work in their communities.

Thank you very much for listening to us. We hope that you'll take our comments and recommendations in your deliberations, and hopefully we can see some of those integrated in your work at the end of your period.

We know that this is a very complex field. Just sitting here and listening to some of the questions earlier around intellectual ability at 70 and why that is a cut-off, issues around where money has gone around residential support, and the complexity of our system in terms of dealing with people who have very little ability to look after themselves and manage, to the other end of people who are living in supported independent living—it's a complex system. I really, quite honestly, don't envy the work that you've got to go through and the arguments that you're going to end up having to hopefully come up with some good recommendations for all of us.

But we're with you, and we are really committed to what we're doing. We really need to feel that there's a fix here somewhere. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. We're really committed to trying to find some solutions as a committee. We're working very hard. Ms. Jones?

Ms. Sylvia Jones: Thank you, gentlemen; excellent presentation. I understand that you're an alliance, so this may be a little more challenging because of your umbrella role, but you are not the first presenter who has made reference to the regulations and the impact that they have on time and cost in your organization.

However, many of the other organizations—I'm talking specifically about the health and safety component of training for violence intervention—say, "We practise complete non-physical intervention, and so this training has no value for our staff. We don't do confinement. We don't do any of that, and yet we're basically forced to train our staff within the first 30 days." Can you comment on that?

1040

Mr. Colin Hamilton: Well, I won't comment on that one specifically. I will comment on the fact that I think we understand that having qualified and trained staff on shift is really, really important. I don't think that any of us in an administrative capacity would sneer at any kind of training that comes along, quite honestly. We really want the training as well. The difficulty is that there isn't the funding to go along with it.

Ms. Sylvia Jones: But shouldn't the training be appropriate for the circumstances that your employees are involved in?

Mr. Colin Hamilton: Yes, but again, those circumstances change from time to time. You may have an admission of someone who is more aggressive, who is

more self-injurious. Then you may be in a position of going, “Oh. Well, we didn’t train any staff on violence interventions. Now maybe we’d better do that.” It changes all the time.

Mr. Robert Morassutti: And in our instance, specifically with Montage, most of the individuals that we support are non-ambulatory. They don’t communicate with words, most of them; there’s other kinds of gestures and indications. They’re not going to be the aggressive crowd that some people associate them with. In our instance, again, there are good de-escalating techniques. There are good situations that can be, I guess, modified in some way with the training. Generally speaking, a lot of what you’re saying in terms of the training being appropriate to the people being served is very true, but as Colin says, we also want to be sure that the staff that we have working are able to deal with whatever situation comes up. It really is one of saying, “What is the most appropriate manner in which to support people in that particular location?”

Ms. Sylvia Jones: Thank you.

Mr. Colin Hamilton: The only other comment, Sylvia, is that the other thing with the violence intervention training is also attitudinal. There are a lot of attitudinal things that go on with that training which are really important for staff as well.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you so much for this presentation. It really, in a succinct way, picks up all the themes that we’ve heard, as of course you know, because you’ve followed along. I think overarchingly, what’s coming through for us, in a sense—and I want to reaffirm that we’re all here to make something happen. We hope this doesn’t become an argument; we hope this becomes a collaborative effort to actually see some change. It’s not an impossibility. Other jurisdictions do it better, so we know that we can do it better, too.

But overarchingly, entitlement versus discretionary keeps coming through over and over and over again, and that’s an attitudinal shift in the way one delivers services. You mentioned that as well. I particularly kind of ring with that. We need to be shifting our mind frame, and all things would flow from that, in a sense, in terms of how we approach the sector.

Any other comments on that shift, if you have them?

Mr. Colin Hamilton: Looking after someone with a developmental disability is expensive, period. It’s expensive. There’s no way around it.

The gentlemen who were here just previously talked about their project, their idea. Again, the issue is sustainability. If you’re going to fund something, it has to be sustainable. Having four or five family groups come together and buy a house and staff it themselves and keep it going: After a while, they’re going to be turning to agencies to say, “We need your help,” which is quite appropriate, and we really do enjoy working with families. But sustainability is the issue.

One of the questions that came up earlier was around that \$42 million that went into the residential supports

piece. I can tell you that in Toronto, we got X amount of money for that, a little over \$1 million for hard-to-serve. That little over \$1 million went to serve five individuals in Toronto—five. For one of those individuals, the price tag was roughly half a million dollars on an annual basis, to support one person. It’s a huge amount of money. Those are the exceptions to the rule, but nevertheless they are there in the province.

Again, when Bob was addressing the hardest to serve, that is the push, but what it also means is that families who were up here before us kind of get left behind—the thousands and thousands of families that are just looking for, “When am I getting some relief in this situation?” Again, it makes it a very complex situation, I know, for you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation and for your passion about this issue. I’m particularly interested to hear more on your last recommendation. You talked about employers needing legislative incentives. Can you elaborate a little bit more about these incentives, and can you share with us some best practices?

Mr. Colin Hamilton: I think the idea here is that there are a lot of individuals who would like to be working in the community. It’s expensive in that many individuals need to be shadowed by a worker before the employer can really assess, I think, “Can the person do it by themselves, or am I always going to need a person shadowing that person?”

So what we’re really looking at, then, is this idea of how we help employers to think about hiring someone with a developmental disability who can do a good job. Their training period is going to be longer. The support they need is going to be longer. That’s where we feel some incentives for employers, on a cash basis, would be really, really helpful.

Ms. Soo Wong: Thank you.

Ms. Mitzie Hunter: Thank you. That makes it clearer. So you’re looking at offsetting wages, more like a transitional employment-type model, and where there’s also paid staff support, job developers, that sort of thing, to help, and also to be there if something does change and needs to be re-explained or settled back down.

Interjection: Right.

Ms. Mitzie Hunter: Okay.

The Chair (Mrs. Laura Albanese): Very quickly, please.

Ms. Mitzie Hunter: That’s it. Thank you.

The Chair (Mrs. Laura Albanese): That’s it?

Ms. Mitzie Hunter: Yes.

The Chair (Mrs. Laura Albanese): Okay. Thank you. I apologize. I have to try to stick to the times, but I want to thank you for coming here this morning, for presenting to the committee. We appreciate, as agencies working on the ground, in the sector, your opinions and your recommendations. They’re very valuable to our committee.

Mr. Colin Hamilton: Thanks very much.

The Chair (Mrs. Laura Albanese): Thank you.

FAITH AND CULTURE INCLUSION NETWORK

The Chair (Mrs. Laura Albanese): We will hear now from Faith and Culture Inclusion Network.

Ms. Soo Wong: Chair, while we're waiting for the next witness, I understand the Ministry of Education is currently working with local school boards as it relates to the Focus on Youth summer employment opportunity to hire summer students. So can we get some direction, through the research department, to find out if there is any focus on the Youth Challenge Fund or the Focus on Youth fund to make sure some of the DD and ID students currently in the various school boards have priority to be hired for the summer program? Because these are provincially funded dollars, is there ear-marking that every school board must—you know, we give every opportunity to every kid, right? So this is a priority we're talking about in developmental services. Is the Ministry of Education—since they're giving funding to hire young people every summer, are there directions or criteria to encourage school boards to hire these exceptional special-needs students so they will have employment opportunities?

The Chair (Mrs. Laura Albanese): Thank you. We'll ask that.

Ms. Mitzie Hunter: In addition to that, while we're looking at the Ministry of Education, the Ministry of Training, Colleges and Universities oversees the youth employment fund, and we do know that a portion of that fund is set aside for people with disabilities. I think we need to ask the specific question about people with developmental disabilities and if there is an opportunity for them to tap into that fund as well for employment opportunities.

The Chair (Mrs. Laura Albanese): Thank you.

Good morning. You now may begin your presentation. You've heard that you have up to 20 minutes, and if it's less than that, we'll allow questions.

Mr. Paul Burston: Absolutely. Yes, and I do thank the committee for this opportunity to present this morning. I'm going to apologize in advance, because you're probably going to hear some similar themes from our presentation and those of others this morning. Hopefully, though, there will be nuggets of something new that you will have to think about.

Also, I apologize for coming by myself. The two people who were to come with me have joined Prime Minister Harper in Israel, so I'm here alone.

Anyway, I'll get right into this, because I do believe that the timing is perfect for addressing the crisis in the developmental service system. There is a crisis.

Faith and Culture Inclusion Network thanks the committee on developmental services for this opportunity to vision together with us to address the concerns and the struggles that families face every day.

1050

It's our intention, through this document presented today, to focus on actions that are critical to the viability of the sector and the support that is needed from our government to recover from years of underfunding at a base level comparative to other sectors. We have been hit harder than most.

Our priorities: Our goal is to modernize and improve our services and supports to people who are in the greatest need, especially those children and youth who have completed their secondary school studies. Our focus is on continuing education to prepare people for the workplace.

Our member agencies consistently strive to develop new approaches to services and supports that move us beyond the group home model wherever possible. We believe that that's an area that we don't give enough attention to. Group homes are extremely expensive. Other options are less expensive.

We will identify systems that inhibit us in achieving these priorities.

It is our intention to keep our comments focused on issues and actions that are critical to keep the sector healthy and the support needed from the select committee in its mandate.

We will provide information that will enable the select committee to make informed and timely recommendations to the government, which address the crisis not only for persons with a disability and families, but also for agencies that provide those services.

You've heard this morning a little bit about the financial pressures regarding the pay equity issue, the proxy method. I don't want to be repetitive, but I have had the opportunity to present to many, many of the finance minister's briefings and have brought this issue forward. It is a flawed method of trying to establish fair and equitable salaries. In fact, what it does is it actually begins to build within our sector inequity, because of the proxy method, as you've heard already this morning, based on hospital workers. What it amounts to is—for example, at the agency that I work for, it is almost \$1 million a year that comes out of our operating budget to address this, which is mandated. It's legal; we have to do it. This affects agencies right across the province. What it amounts to is that with the proxy method, the spread, when we looked at this years ago, was a salary of between \$18 an hour and \$38 an hour. Of course, within our sector, there really wasn't any major inequity between a female worker and a male worker. We were simply all poor. Although pay equity has helped in improving salaries for people, it is, as I say, a flawed method and it really needs to be looked at in terms of what is a reasonable salary within our sector for our professional support people.

The simple solution—and we've heard a lot about things being complex, and very often things are complex because we make them that way. What I would suggest is that the select committee recommend that the government rescind the proxy method of determining pay equity and establish a reasonable sector norm of pay equity, and

develop a multi-year funding plan to achieve it. Then we can put this thing to bed, because it's just been going on for years and years. In fact, some organizations are going to be doing this pay equity stuff for another 10 or 15 years. It's ridiculous.

We have been doing our part to work within significant financial restraints while at the same time coping with increased regulatory requirements that demand of our staff and leaders that they spend considerable time away from supporting people to supporting administrative duties.

It is imperative that the government recalibrate its priorities for the developmental services sector and accomplish this without endangering the fragile economic recovery, and free up agencies to manage what they do best without extensive bureaucratic requirements.

It is also important that our comments are not received as member agencies pointing a finger or playing the blame game. It is, however, reasonable to say that when the government and a non-partisan committee asks for input from the sector, it will do so with active listening and a real commitment to work together to resolve the crisis. I've heard that that's your agenda, and I was happy to hear that this morning.

Operational systems: The challenge families and agencies face is the impact of operational systems that add little or no value to the people in need of services and support. Our collective goals are frustrated due to forced long-term budget restraints, misguided priorities, inappropriate systems and a lack of vision for the sector.

Our current systems of operation have, in fact, not only complicated our work but are pushing us into a system that is not functional. Instead of facilitating needed changes, we are continually forced into restrictive processes that are achieving nothing to reduce the current crisis in the system or to modernize it. This is particularly true with the implementation of Developmental Services Ontario, the DSO. Their mandate has no resemblance to the reality of our work or the services that families require. Often, families do not feel supported by them. The DSO model has resulted in significant burdens on agencies within the sector. Restrictive, prescriptive requirements have been implemented. These requirements were intended to establish accountability for service delivery, as well as equity, but are in fact constraining the performance of both the DSO and agencies engaged in the delivery of services, resulting in diminished results for those we support.

We support the ongoing need to modernize our system. What the sector requires, though, is the development of clear and agreed-upon service delivery outcomes and the flexibility for agencies to collaborate on the appropriate means by which those outcomes are met. Again, restrictive, prescriptive bureaucratic systems leave no room for flexibility and innovation, which is needed to respond to service delivery demands. Sustaining these approaches inevitably leads to a focus on the systems themselves and detracts from the needs of those who need to be served.

The DSO goals also include that vacancies are to be filled by those most in need. The inconvenient truth is that those most in need are often inappropriate for the vacancies that are declared by agencies, due to their high needs and the lack of adequate funding, or their incompatibility with the persons that they're being asked to live with.

Following the process required through the DSO leaves agencies absolutely no room for creativity or for the modernization of services. We are simply recreating current services. This is a major issue, in that an agency will declare—we're looking at almost a health system mentality: There's a vacancy; get that bed filled as quickly as you can. What it does is it just recreates what's already there, and we know that's not working. It's not working properly, anyway.

Ontario has experienced great transformation in its view of its citizens who have developmental disabilities, often society's most vulnerable. History tends to repeat itself. Much effort is needed in order to help Ontario to continue to transform the image of its most vulnerable citizens, and we believe the following actions will help in this endeavour: that the government, in partnership with agencies, determine targeted reductions in the waiting lists as a first priority and, together, commit to eliminating the waiting lists within 10 years. This multi-year plan was used to close institutions in Ontario and was successful because of a shared vision and outcome by all stakeholders. I was part of that system. I've worked in the system for 43 years, starting in the institutions. The only reason the institutions were closed is because all parties got together and said, "This is not acceptable. People with disabilities need to be part of their community." So when we say that government can't be all things to all people, what we're really saying is that people with developmental disabilities are not deserving of the care that they need and the support that they need. I think that's a wrong focus to have because all the time that we plan from scarcity will always lead to inadequacies within our sector. We need to understand that.

1100

I've talked about the need for multi-year funding within the sector each year until the wait-list is eliminated, and I will add that that needs to be done while we modernize services. We can't just keep recreating what is already there. You've just heard that group homes should be the last priority, not the first, for families. Group homes are really there for people who have significant needs and need a safe environment in which to live, but many people, many on a waiting list, are people who can live more independently and be supported far more efficiently than a group home will ever be able to do.

Review the mandate of Developmental Services Ontario, the DSO. The intent of the DSO is good; it's the implementation and the focus that they bring, based on inadequate and wrong priorities within the regulatory piece of that. One of the things that this committee can do is say, "We need someone to look at how DSOs operate in the province to make them more effective."

Failing that, we would be better off with a collaborative system that was enjoyed here in Toronto for many years and worked really well, and it didn't cost any money, as opposed to \$20 million right now.

The Select Committee on Developmental Services should convey to the Minister of Finance, as I've been doing for a number of years, that government-funded services target the financial gap accumulated over five years of zero increases to our sector.

This is another important element: continued support for creating real employment solutions for people with developmental disabilities to find gainful employment and reduce the amount of people relying on Ontario's disability support.

The lessons learned from Huronia: The recent court action regarding abuse in the Huronia institution and the subsequent settlement should inform all of us of our social responsibility and our collective duty to protect and support our most vulnerable citizens. We believe we can agree that the history of past abuses is not one we would want to repeat, and this should be the driving force that informs us all of our responsibility and which should, in fact, direct government policy.

In conclusion, we believe that there is an opportunity to be more fully engaged with the agencies and in the sector planning process to develop accountability mechanisms that focus on developmental services outcomes and principle-based approaches to ensuring continuity of service delivery while maximizing flexibility and innovation in a citizen-centric model focused on the needs of those being served and not having to serve unnecessary bureaucratic systems.

The question each of us as leaders needs to ask ourselves today is: Do current funding levels for the developmental services sector reflect the value we place on people with disabilities in Ontario?

Although a lack of adequate funding for the sector may not be a conscious action on our collective part, we need to reflect on this question, as it will help all of us re-evaluate our priorities in support of funding needed services for the most vulnerable.

Respectfully, members of the Faith and Culture Inclusion Network request that members of the select committee note that although there are seven recommendations, which I've just given you, many do not require significant additional funding. However, some do require reallocation of funds and the elimination of wasteful bureaucracy and an outdated process for establishing pay equity within the developmental services sector.

The long-term strategy that the government must have is a vision that would see the elimination of wait-lists over 10 years and the courage to promote a social responsibility tax for that purpose. Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much. We have about a minute each, so one question each, starting with the NDP. Ms. DiNovo?

Ms. Cheri DiNovo: Yes, thank you very much. Again, of course, as you're aware, we're hearing themes here, and you've just buttressed those themes, so thank you for doing that.

I have a question, actually, for research. I heard you quote \$20 million for the DSO; I've heard others say \$12 million, so that raises the issue: How much does the DSO cost us every year? I'd like an answer to that. Thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Thank you so much for your presentation. One of the things you pointed out was the DSO's role in vacancy management. The intent is to have this sort of aggregated and that prioritization is dealt with as efficiently as possible. But sometimes there's a mismatch between the person's specific needs, particularly those that are most complex, and the available residential space.

Mr. Paul Burston: That's usually the case, because the way it operates is the most in need get that first opportunity for any vacancies. The most in need are more than often people with very complex and challenging needs. So what happens is the vacancies that are declared, they do not fit, and it would be inappropriate for those to be placed there. So there's a certain level of disconnect with agencies and families and filling spaces appropriately, and the lack of flexibility as well in terms of looking at existing housing stock. We've heard about the fire regulations, the building regulations, the accessibility, making some of our housing obsolete.

This is a great opportunity to work with the DSOs, if they were permitted, and with the ministry, to say, "What do we do?" How do we change our housing options so that we don't have to be worrying over every little thing around fire regs and accessibility, when we can probably inhabit buildings or have buildings that meet all those requirements? The group home is so expensive.

The Chair (Mrs. Laura Albanese): Thank you. Mrs. Elliott.

Mrs. Christine Elliott: Thank you. There are many questions I'd like to ask you because you've raised some really important new ideas here. But I will ask you about the DSOs, because we have spent a lot of time on them in your presentation. I guess my basic question is, do you think it's enough just to revisit what the DSOs are doing, or do you think that there is another way that we could deliver the same services without costing as much money, in another form?

Mr. Paul Burston: I believe that we had a system in place prior to the development of DSOs—the principles of one entry into the service system were already there. I know agencies in our group were a part of lead agencies that dealt with that. What that did for us was it allowed us to get to know the families more intimately. It's not just a piece of paper and filling out a form. It's about getting to know people. It's about building relationships. It's about the ability to offer other options. It's about the ability to know that what might work for this family might be respite for the next few years, before they enter into any more intrusive type of care. Families are just looking sometimes for a break, and all they can think of is group homes. That's part of the problem.

There was a system; it was working well. In fact, the minister at the time—I begged, "Please don't do that. It's

costly.” We had an experience in Ottawa where—this is a number of years ago—several millions of dollars were spent every year, but not another single person was served in the system. We’re faced with the same thing today, really. The creativity that agencies have been good at is actually being stifled because we’ve got to follow this bureaucratic system. Unless the DSOs can be asked to recalibrate their approach and given some of the freedom to make decisions that we used to make as a collective, I don’t know how that will happen.

If I may, just very quickly, we had an experience where we planned for a person, and it took three months to fill this vacancy through the DSO process, which contravenes everything that they were put in place for. The weekend that the person was to move in, the family decided, “Well, that’s just too far for us to drive.” What that says to me is that we did not have the kind of information and the kind of relationship with that family that would have facilitated that change, so there’s a problem.

There are several options that are before us. One is the collaborative approach, which is less expensive or not a cost to the government. There is continuing to build into a bureaucratic system that’s not actually reflecting the needs of families. Families are coming back to agencies right now, asking for help, because they can’t get it at DSO.

1110

The Chair (Mrs. Laura Albanese): Thank you very much. We really appreciate your presentation this morning.

Mr. Paul Burston: Thank you so much for your patience and listening. I appreciate it so much.

MR. HAROLD BRENNAN

MS. DEBBIE BRENNAN

The Chair (Mrs. Laura Albanese): We’ll now ask Debbie Brennan and Harold Brennan to come forward. Good morning. Welcome to our committee. You may start the presentation any time you feel ready.

Mr. Harold Brennan: Good morning, honourable members Albanese, Elliott, Balkissoon, Hunter, Jackson, Jones, Taylor, Wong, Clerk Day and any other members of the committee. First of all, thank you very much for the opportunity to be here today. We’re Harold and Debbie Brennan of Belleville, Ontario, and we’re here today as advocates for our 24-year-old son. As I read this the other night, I thought, “That sounds an awful lot like an intro to *Dragons’ Den*,” but I believe this is a much more friendly environment here today.

Today we’re going to bring you a very personal story, a very grassroots story. But before we launch into that, the stated mandate of this committee—I’m sure you all know, but it’s also important for you to know that we have read the mandate of your committee and read the objectives, and congratulate you on tackling such a momentous issue.

Your strategy lists six issues that you’re going to take a hard look at. Based on our son’s age, we’ve already gone through the first two of your issues, to do with education and early years. We’re going to deal with the remaining four—they certainly are very relevant—and we’re going to revisit all four in our presentation later.

To help you understand our focus and some of the reasons we’re here, we’d like to read you a letter that we sent to six elected officials—I see some of them around this table—in September. We completed a follow-up in December. I want to take a bit of time and just have that letter read to you, because it helps frame the perspective from which we come.

Debbie, my right hand in everything for the last 30-some-odd years, is going to read the letter. She’s the author of the letter, and she also is the primary caregiver for our son.

Ms. Debbie Brennan: “Our 23-year-old son was a year old when our fears were first confirmed. We learned that my dream of having a child who I could dote upon and my interest in children with special needs had collided to present us with a child who, despite our best efforts and devotion, for 23 years would ever remain like a toddler.

“He was born with a chromosomal deletion named 1p-, and he bears the pain, anguish, complications and effects of severe global developmental delays, autistic tendencies, seizures, awkward gait, skeletal deformities, feeding challenges complicated by choking incidences, incontinence of bowel and bladder, anxiety, aphasia, behavioural and intellectual challenges.

“As I told his grandparents after he was diagnosed, ‘He will be okay. Harold and I are prepared. We will handle this. We are in a better position than many families, and I am very thankful’—to this day, I can even say that—“‘that he is in this one.’ I assured them that the world had changed and that, with proper planning, he would and could have options and an enriched life.

“As a unit, our family rallied and devoted time, effort, expense and made huge emotional, physical investments in making him part of the family and community, while doing our best to provide a safe, healthy and enriched life for him.

“We began responsible planning for his future with Community Living Belleville and Area in 2004 with great confidence and hope, and participated in numerous meetings to discuss long-term placements, housing, community support, parental and financial responsibilities and the necessity of involvement of professionals to ensure a safe, fulfilled environment for our son, beginning at age 21, until their services were no longer needed.

“Until recently, I believed that we had been successful in achieving this plan. At 23”—he’s 24 now; I wrote this letter a few months ago—“our son still resides with us. His physical and intellectual disability result in him having the skill set and receptive language level comparable to that of a toddler. For the most part, his condition remains unchanged.

“I wish I could say the same for Harold and I. We are heartbroken, disappointed, exhausted and fearful that we

and he are in the very position that we had planned and worked so desperately to avoid. We are seniors who have faced those associated challenges and have little hope for his future. Despite our efforts, both professionally and personally and by Community Living over nine years, we have been unable to secure a safe, suitable and long-term placement that meets his physical, safety, community support, intellectual and supervisory needs.

"It was hoped and planned that a recent respite placement would evolve into a long-term home. After two agonizing years of observation and assessment, it has proven a failure with respect to meeting his needs. It is our understanding that occasional funded spots that become available are not suitable due to elevated safety risks from others living in those homes and grave infringements on the rights of him and others in those homes.

"Many years ago, we were participants with a group of five families who shared the challenges and hope of suitable housing for our children. For a variety of reasons, such as family transfers and the health concerns of families and children, the group disbanded.

"Temporary housing options such as basement apartments outside of town were ruled out due to safety issues and community isolation. Extensive efforts by managers at Community Living have been unable to secure temporary support options such as those provided by the associate family program and reverse planning options.

"We have contacted other families on our own who share our concerns, have similar needs and have discussed options outside those provided by service agencies. No options are seemingly possible without secured and adequate funding.

"Concerns have been voiced by professionals involved with our son regarding his ability to transition. The longer he waits, the older he gets when he is faced with a transition to a permanent home, thus adding to the urgency of this situation.

"Our son is now a 23-year-old man with a severe developmental disability. We've grown older and are faced with fears for our future as well as his, and we can no longer imagine a retirement whereby we can look forward to visits from all our children, our son included. Now in our late 50s, we struggle with sleepless nights wherein he might be up for the day at 3 a.m., leaving me irritable, teary and less able to make sound decisions. On occasions, I have struggled to remember if I have even properly followed his medical protocol.

"Harold is working. Such nights interfere with his sleep, as he takes his shift when I am no longer able to cope. We are both awaiting appointments for day surgery; while we should be focused on our health, it is his safety, health and future well-being that dominate and dictate our thoughts, our leisure, our appointments, our financial fears and decisions, and our ability to fulfill our commitments to our daughters and aging parents.

"For the most part, our lives involve a tag-team, turn-taking approach as to who is watching or staying home with him. We do not attend family events with him, as

he's unable to handle the commotion. Some events can be accommodated in advance, but spontaneous events such as the onset of illness become a challenge for us to manage because of his high needs.

"If I'm home alone with a migraine, I hesitate to take the proper medication for fear of becoming drowsy and unable to provide proper care. I take medication for high blood pressure and recognize the signs of its elevation, but have no choice but to power through tough times when I have no options or alternatives.

"Our physical health is reflective of our plight. Harold has two herniated discs and has given up some sports as a result of pain management, but it is difficult to avoid the physical needs of a toddler. Every night, Harold stays up later than I do to change our son before we settle for night. Our son is groggy at that point, requiring him being lifted onto our custom-made change table.

"Because of his limitations, needs and behaviours, there are huge amounts of laundry, household tasks and meal preparation to be completed. At an ODSP tribunal last year, I gave testimony regarding the work and effort involved in caring for him, his physical environment and his activities of daily living. When the judgment was handed down, it was acknowledged that the activities required for adequate care for him resembled those of an institution.

"It goes without saying that, after 23 years of lifting, excess stair-climbing and changing beds, my sore shoulder and hips are symptomatic of our parental responsibilities and complicated by our age. We struggle to but are trying to accept and manage the physical and custodial aspects of caring for our son.

1120

"But it is the mental torment, worry and fear for his future that we can no longer live with or cope with. When lying awake at night, I struggle to see how we would have done things differently, how things would have changed for him and his future. We accepted his plight, ours and those of his devoted sisters many years ago.

"When we began responsible planning for his future with the respectable, capable advocating agency with whom we worked to secure long-term care that was safe and properly staffed and that shared our goal of a happy, enriched life for him that recognized his strengths and weaknesses, we met with their managers as well as other professionals in the community, which included lawyers and accountants, to make sure we were on the right track when planning for him. It has become painfully clear that we are at a dead end and that there is no track and, quite frankly, no hope.

"I am disillusioned and have no confidence in a system that does not have or seems unable to have the best interests of our son in mind or often in their sight. It turns out that the fears of my parents, who I reassured years ago that the world and society had changed for the better, were realistic and accurate after all.

"We are willing and expect to continue to fulfill our responsibilities as his parents, but in the absence of

adequate sustained funding, he will be sentenced to a life that agencies and officials with decision-making power can and have ignored and denied. As his mother, I refuse to accept that reality.

“Over the years, I have read about the plight of parents who, in their desperation, went public with their story. I wondered why they had been unable to plan, to organize, to meet with officials to discuss their responsibilities in creating an enriched life for their child, as we had done and as we were doing. It turns out that our work, our efforts, as well as those at Community Living, over a period of nine years have proven futile and were in vain, as we are at the same dead end and share the same feelings as those people who I once thought were desperate, deserving of insight, financial support and peace of mind.”

Mr. Harold Brennan: Now that you have a clear understanding of our perspective, we would like to reflect on where we are now as well as have some dialogue around the four focus points mentioned earlier. We also want to talk about what we have accomplished for our son's planning and some of the ideas around viable solutions that we feel would be positive not only for our son but for many others in Ontario who suffer from a disability.

The perspective we're bringing to this is that we are dealing with a 60-year problem here because of our son's natural life expectancy, so it's not something that's going to go away short-term.

The committee focus points: The first one that we're going to deal with is the need to provide social, recreational and inclusionary opportunities. We obviously fully agree with the focus, and we have in fact been able to establish all three of those criteria. We've got them in place in his community. The problem is the sustainability of these objectives. We have opened the doors and laid the groundwork. We have that in place, clearly, all those items, but we need the staff to provide the care, support, guidance and delivery to sustain these objectives. Formerly, a lot of this delivery was through the school system and through his siblings, but because of his age and because his sisters are older and have now moved on to their own lives, that support system no longer is there. So the issue is the absence of perpetual funding to maintain what we have built.

The second one we talk about is the need for a range of affordable housing options. Again, we fully agree with the focus, and we believe that the population we are talking about, really, regardless of personal income level, should have similar housing environments as any other single Ontarian would. There should be no more than one to three people living in a home. That's what most people would expect, so why would we look at this sector and say, “Well, no. Because you're this way, you get to live with six or seven”? I think the perspective should be the same as if they didn't have an intellectual disability.

We feel that publicly funded homes in our communities should be made available, maintained and staffed as sustainable and safe homes. Our attempts to

ensure such housing for our son have been in vain so far. We worked, as Deb mentioned, for the last nine years. So we have personally purchased a home. It's an appropriate house that can meet the structural, social, environmental and inclusive needs either permanently or temporarily. We're flexible to go either way; it depends on the future availability of safe and sustainable publicly funded homes.

We feel we should not have to, but are willing to, provide the physical environment at well below market rate. The problem is the sustainability. Now, if we look at the cost of staffing on the publicly funded model—and we've used the numbers from a transfer agency—you're looking at about \$280,000 for one-to-one funding. We feel that the funding can be done for about 60% of that on a one-to-one. If we look at more of a private-sector type cost structure as opposed to a public cost structure, it runs at about 60% to 64.5%. To basically make this more efficient, we're willing to work with other families that are like-minded and compatible. In addition, we need the support of public agencies that have rid themselves of old-world, inefficient thinking; so they've got to change. We need the agencies to provide services such as staffing rosters, human resource management, payroll management, staff screening, med training, liaison with related agencies, continuing education etc. That's what we see we need them for.

The next focus: the respite and support needs of families. This focus, from our point of view and experience, goes hand in glove with the previous focus. The primary difference, of course, is that respite and support, on average, is a need that increases from childhood to adulthood.

If there is adequate, proper, quality housing and, more importantly, adequate, quality staff based on needs, not budget, then both of the above focuses will be met.

The next focus: how governments should most appropriately support these needs and provide these opportunities. First of all, we do not envy you, as our government, trying to balance the wishes and needs of such a diverse population like in Ontario. Our sense is that the answer to this focus is very personal, and we've given this a lot of thought. Our single most important thought is that those with disabilities should be treated with no less respect than other publicly funded stakeholders.

We haven't figured out the answer, so we don't get to be your last speaker. We didn't bring the magic bullet with us today. If we had it, we would have forewarned you.

Again, we hope not to offend anyone with our thoughts here today, but we feel we need to take a look at some things. Primarily, we have to have a philosophical change and refocus in the public sector workplace. We need to engage outside-the-box thinking from sector benefactors and their advocates. We need to employ models that encourage private sector engagement.

We feel the number one priority must be that people in need must be the number one benefactor of every decision and every dollar, and the rest of us have to take a second seat. And by “the rest of us,” I mean the rest of

us: I'm talking about politicians, taxpayers, parents, siblings, public employees, private employees—everybody else but those we serve.

The way we have supported people with disabilities in the past is not how we feel they should be supported in the future. We must take vision and mission statements off the walls of agencies and turn them into practice. We have to accept the sacrifice that it takes to do that, and you will get to the benefactor being the person with the disability.

We need to refocus from the present, whereby employers and employees are being beneficiaries of the system ahead of those we serve. It's an unfortunate reality that we see. The individuals with disabilities have to be number one, not number two, three, four or five.

We realize these are very heady objectives, and some thoughts that we hope may have some merit and in some small way improve the system of support for those we're all trying to support—it ended up being a total of eight:

The funding, we feel, must attach to the individual, not an organization.

Organizations should consider a modernized employee model, not a continuation of the current model, as it has proven financially non-sustainable. When I hear math up here about 80%, 85% into staffing—I'm in private business, and that's about 20% to 30% above what would be seen in the private sector. We think that having more private sector support in this area is going to really free up a lot of dollars to get available to provide service to more people at a higher level.

Government ministries need to work together, and I'm sure you are, to efficiently deliver to the individual needs. Ministries, in our opinion, that were coming into play here are social services, the health ministry, the finance ministry, children and youth services and, to a lesser extent, colleges and universities.

Advocates need to be revenue-neutral-to-negative, and when involved with financial management of public funds, we need to be fully accountable and audit-ready.

1130

Government ministries should take a look at making it attractive for the private sector to participate at a much higher level than current. I think this is an area of opportunity for additional funding in an efficient manner. An example here would be for the Ministry of Finance to fast-track applications for small micro-boards as non-profits. It would be able to make it viable for local organizations, individuals and charitable foundations to contribute to local needs.

The new world model would embrace in action, not just in word, the tools that are out there. They'd actually be more ready to use behavioural consultants, occupational therapists, technology and dietary specialists. Those services are out there and there's a lot of chatter about them, but our experience has been they don't get applied as much as they get talked about. We need to make sure that there are no impairments to services.

Last but not least, we have to revisit the budget process. Unfortunately, it is always about the money. We

feel, based on the current environment, that the vulnerable of our province are getting less money than some other sectors.

We're running out of time here, so I want to give you at least a minute or two to ask us a question.

The Chair (Mrs. Laura Albanese): Unfortunately—

Mr. Harold Brennan: We're all out?

The Chair (Mrs. Laura Albanese): We're over the time and we won't be able to ask any questions. First of all, I want to thank you for your compelling and frank presentation. I want to commend you for all that you're doing thus far for your son. I just want to assure you that we will be taking all your recommendations into account. We thank you for being here today.

Mr. Harold Brennan: Thank you very much. We appreciate the opportunity.

Ms. Debbie Brennan: Thank you.

MS. ROSANNE RENZETTI

The Chair (Mrs. Laura Albanese): I'll now call on Rosanne Renzetti to come forward. Good morning. Welcome to our committee.

Ms. Rosanne Renzetti: Good morning. Thank you for having me. I just have a really simple handout today, so I hope you all have that.

The Chair (Mrs. Laura Albanese): It's being distributed; we'll get it momentarily. You may start in the meantime.

Ms. Rosanne Renzetti: Thank you. I'd just like to thank the committee for allowing myself and other parents an opportunity to share our experiences, and I'd like to particularly thank Ms. Elliott for introducing the resolution that created this committee.

I'll largely be focusing on the needs of children and youth with autism from personal experience. My daughter is eight. She is on the autism spectrum. She is a cheerful, sweet, affectionate girl who is extraordinarily active. I sympathize with our last speakers about staying up all night; we do that a lot, too. She also has a number of challenges, including language limitations and social impairments, as well as the anxiety, cognitive delays and sensory processing issues that many children with autism face.

I recognize that you've heard from and will continue to hear from many parents who have children with severe or multiple disabilities, parents who are struggling to cope with incredible challenges, and that in comparison, our situation may seem less dire and may not seem to warrant the same urgency as others. However, our story is not unique. It's one that I've heard anecdotally from many other parents, and the fact that so many of us have had similar experiences makes me think that it is a story worth hearing once more. That's what compelled me to come here today.

I'd like to make some very general recommendations, just based on our experiences in the last six years, and the supports and services that would have improved our experience and our daughter's outcomes. My focus today

will be on diagnosis and early intervention and what I call ongoing and inclusive support. I will get into more detail as I go on.

Starting with diagnosis and early intervention, this is our story: My daughter was diagnosed as being on the autism spectrum shortly after her third birthday. It was not an easy diagnosis to obtain. Her former pediatrician refused to believe that any of her symptoms were cause for concern, and it took six months of persistent lobbying on our part to convince him to examine her situation more closely.

After admitting she likely had autism, he would not give us a diagnosis but insisted that we receive a formal diagnosis through a local autism services agency. When we called and found out that the waiting list for diagnosis was at least a year, we called the pediatrician back and asked for other options to speed up the diagnosis process, thinking that a diagnosis would help us get her services. He told us to just get on the wait-list and wait.

Thus began the first of many typical encounters with government services. Whether a doctor, a staff member from an autism agency, or a school principal, each one understood their role in my daughter's life in the narrowest and most strictly defined terms possible and no more. If their role was to refer, they referred. If their role was to redirect us to other services, they redirected. If their role was to apply the Education Act as narrowly as possible, they did so. If there was anyone with a comprehensive view of the system whose role it was to guide us through the complexities of autism services in this province and ensure my child's best interests were being served, that person did not exist for us. We became that person.

As parents, more often than not, we were left to put the pieces together on our own: to make the endless phone calls, fill out the same information on numerous application forms, to advocate tirelessly with multiple levels of government on behalf of our child. More often than not, we simply had to resort to privately funding interventions for lack of any other option. My husband and I are both university-educated, English is our first language, we are trained researchers both, and my husband has a law degree. And yet, with all these strengths, we could barely cope with the strain of finding services, understanding the larger system, including the education system—just understanding it—and struggling to pay for private services when we could not bear the thought of wasting precious time on wait-lists.

To this day, we wonder: What happens to the families who do not speak English or French as their first language, who are not familiar with the inner workings of government and simply cannot make the financial sacrifices required to go beyond the system when it fails them? This goes back to my first point of diagnosis and early intervention. I don't make a lot of detailed points; I'm thinking broad strokes here. We need to ensure that there is an abundance of centralized caseworkers. I didn't even know what a caseworker was until probably three or four years after my daughter was diagnosed and someone asked me if I had one. I had no clue what that was

because we were simply never offered that option. There simply—whatever the system of delivery—has to be more support for parents from the moment an issue with developmental delay is suspected. I'd like to see a definite reduced wait time for diagnoses.

I ask a few broad questions: Can we empower our family doctors and regulated health professionals to deliver more initial diagnoses if that speeds up the process? Have we made it as easy as possible for these individuals, as well as teachers and early childhood educators, to make referrals for diagnosis? Can we envision a system where we provide interventions and recommend them to parents while parents are still waiting for an official diagnosis? In many cases, children with developmental delays could benefit from interventions from day one. There are general ones that could benefit many, many children in many different situations. We can start providing those even before we start to stream them towards one specific group of funding or another.

Ongoing and inclusive support is the next area I want to focus on as my second bullet point. Here I'm proposing something a little whacky maybe. I'm looking for something that's ministry-neutral. If we're going to have caseworkers or agencies, I'd like to see them work more effectively across ministries to help guide parents and children through the system, regardless of who is providing the services.

I'd also like to see a vision where these same agencies and/or caseworkers are working through broader time periods. Those of you who have children with disabilities or developmental delays know that it just sometimes takes longer to get to different points in their life. We feel that sometimes it's rather arbitrary. You get funding for a certain period in their life, and then it's cut off and then you're moved to another period. You're not ready for that period, necessarily. If I had a caseworker who could follow my child, let's say, from infancy through preschool, and then perhaps a different caseworker who works her through her primary and junior years, that would make a lot more sense in the development of the child and the child's specific needs.

I'd like to see agencies and caseworkers who can respond to the changing needs of children as they grow and progress and they require different supports or therapeutic interventions, not just one, whatever they need at that point in their life, which is constantly going to be changing, as they change and grow.

I'd like to see interventions and therapy as part of the classroom experience. Let's stop dividing our educational supports from the therapeutic ones. In her short life, my child has undergone speech therapy, occupational therapy, physical therapy, behavioural interventions and social skills therapy. That's not even getting into the medical stuff. We had to carve out the time and funding to pursue these therapies outside of her regular school day, or cut them out entirely and watch our child regress.

In a daycare setting, I found that daycares were generally more open to allowing private therapists to come in. This was generally not allowed in a school setting.

Ideally, we should provide a school system that has a holistic approach, very similar to the child and family-centred approach that the Bloorview School Authority here in Toronto has, for example. If that's impossible, then we need a means by which private therapists can be approved by the ministry and/or school boards to provide interventions and supports. I get that this is a Pandora's box in terms of regulation and monitoring and providing a two-tiered system; I'm certainly not a proponent of it. But the reality is, we have parents who are giving up paid employment to volunteer in their child's classrooms or who are paying therapists to volunteer in classrooms in order to get around the limitations of the system.

1140

In my bullet point about ongoing and inclusive support, I'm using the term "inclusive" a little differently than it's usually used in the disability community. It usually refers to integration. I'm talking about it in a slightly different way, and I'll explain why. At the time of my daughter's diagnosis, most funding for autism services was aimed at children under the age of six. This was in the form of applied behaviour analysis, ABA, or intensive behavioural intervention, IBI. This is what was approved by the province. It was believed to be most effective when started early. In order to receive funding for this therapy, you had to bring your child to an assessment centre to see if they qualified. So having a diagnosis in hand wasn't enough; you had to be assessed at an approved centre.

While there was no doubt on the part of the team who assessed my child that she was on the autism spectrum, she was well behaved at her assessment and spoke one or two words—not directed to anyone or not in anything that would indicate an understanding of communication, but she spoke. Based on this one-time, 10-minute observation where she spoke once and the fact that she did not scream, cry or trash the room, she was deemed to be too high-functioning to receive funding.

Fast forward to two years later: She's finishing kindergarten at our local school. We are struggling through an IPRC with the Toronto school board. We have a child who still has the same autism diagnosis and who clearly will not be able to cope in a regular classroom without support. While we have accepted that integration has benefits, we know that she would benefit academically from being in a classroom with autism supports. The school board requires an assessment from their own psychologist before placement. Why? She has a diagnosis. Well, in Toronto, the autism special education program is limited to children with average or above-average intelligence, despite the fact that 75% of people on the autism spectrum have some sort of cognitive delay.

To put it bluntly, my child was too bright to receive financial support for autism therapy and too dumb to receive the autism-specific educational supports she desperately required in school. It is in many ways difficult enough to cope with your child's limitations, but it is insensitive at best and, frankly, discriminatory at

worst, to use these cognitive deficits to determine whether she deserves supports. We need to stop discriminating on the basis of diagnosis and intellectual ability.

The Auditor General of Ontario did a very comprehensive report this year as part of the 2013 audit. "Reports on Value-for-Money Audits," section 3.01, focused on autism services. It's an excellent review of the issues around wait-lists and lack of consistency across the province. The Auditor General points out that clinical research demonstrates that children with mild forms of autism would enormously benefit from IBI, but they are presently being denied the service because it is only available to children deemed more severe, who in some cases do not benefit as much. The Auditor General goes on to note, "According to experts, early diagnosis and treatment ... might reduce the need for more supports and services later on in life." This has been proven over and over again. So it stands to reason that we're reducing long-term costs by extending these services to all children, regardless of severity.

I would like to extend what the Auditor General says and say that we need to calculate another hidden cost, that borne by the health care system—and I think the previous speakers have demonstrated that amply. I can't speak for them, but I can certainly say that many of the parents I have met seem to deal with an inordinate amount of stress, part of which comes from coping with the actual situation, but a great deal of which comes from the very preventable stresses of navigating the system. It is very difficult to be constantly reminded by every government agency of the urgent need for intervention before the age of six, while simultaneously being presented with every obstacle possible to receiving that intervention. This takes a toll on your physical and mental health. Other parents and I also have to cope with the financial stresses of providing therapies, as well as setting aside funds for future support.

I was somewhat concerned to read a recent University of Calgary study from their School of Public Policy. They did a cross-Canada study, across many provinces, which reported that lifetime autism costs, including the actual expenses plus the cost of caregiver time and caregiver lost potential earnings, ranged from \$1.2 million to \$4.7 million for a typical person with ASD.

Once again, going to my point on ongoing and inclusive support, we need to provide a range of services regardless of the specificity of the diagnosis or the severity of the disability. It's not about the diagnosis or the severity; it's about the access to consistent, frequent and appropriate intervention and support for your children.

That's all I have to say today. Hopefully I shaved a bit of time off. I know everybody has run over.

The Chair (Mrs. Laura Albanese): Thank you. There are about two minutes for each party, and please do not go over. We're already running late. Ms. Hunter?

Ms. Mitzie Hunter: Thank you so much for sharing your story. It definitely reflects what we have been hearing as we've been conducting these hearings across

the province. The issue of diagnoses, the issue of treatment—and appropriate treatment and intervention at the right time is a particular theme that has emerged. I think that you've very much given us additional ideas, such as teacher referrals, the roles that doctors could play, and relaxing the system so that we can get to the business of providing assistance to the children, so I want to thank you for that.

I've also noted the holistic approach as a new thought that we can think about in terms of, what are the other wraparound supports that people need?

I'm also hearing—as a parent; as we've heard from all of the families—the need for relief, and for the system to be working with you and not against you.

So I want to say thank you for giving us this very simple one-pager and for so eloquently expanding on it.

The Chair (Mrs. Laura Albanese): Ms. Elliott?

Mrs. Christine Elliott: Thank you very much, Ms. Renzetti, for being here and for your continued advocacy on this issue.

Ms. Rosanne Renzetti: May I say, Ms. Elliott, that I hate the word “advocacy”?

Mrs. Christine Elliott: Okay.

Ms. Rosanne Renzetti: I just want that to go into Hansard. I really think that in an ideal system, I wouldn't have to advocate for my child's basic rights. Sorry. I'm sure you had something more important to say than that—but I'm never going to be on the record again, so I might as well.

Mrs. Christine Elliott: Well, I quite agree with you that you need to. I think that's the situation most parents find themselves in: that you have to do that in order to get the services you need for your child. So the concept of system navigators just to help you get through the system, and even to inform you about some of the services that are available, is so important.

Ms. Rosanne Renzetti: Absolutely.

Mrs. Christine Elliott: I'd like to ask you a question, actually, on another point that you made, and that was about not dividing therapeutic and educational supports. We've heard that from other parents—parents whose children may have been involved with a children's treatment centre, and then when they're school age, of course, those supports are cut off. The therapists can't come into the classroom, and families find that extremely disruptive, and then they don't get systems and services picked up when they go into the school system. I'm wondering if you could comment just a bit more on that, and what it meant to you and your daughter.

Ms. Rosanne Renzetti: Absolutely. I think it's a bit of a fallacy that we've somehow spun—in the autism community, at least—that you get to them before the age of six and then they're miraculously cured. I think everyone knows that while you make great gains in the primary years, there are certainly things that still need to be worked on. My daughter still required a great deal of occupational therapy for sensory integration issues. Her speech had improved somewhat, but she certainly hasn't made enormous leaps, and she could have benefited from having those things

Because we could not do it in the school system, my husband and I basically had an impossible work schedule, where we'd pick her up from school, drive her halfway across the city, engage in therapy, come home, vaguely remember that we had another child somewhere, pick that child up, come home and go through our regular day. We could do that two or three days a week, plus huge chunks of the weekend—to try to cram all of that therapy in while continuing with a regular school day. At a certain point, we realized that it was just taking a very detrimental toll on our mental and physical health, because we couldn't sustain that pace. But we still feel that she needed those interventions.

In the school system in Toronto, at least, their model has been to provide consulting. So you might get an occupational therapist, five months after you ask for one, to come in and spend 10 minutes in the classroom and provide the teacher with some supports. It's simply not enough. I think we know that teachers are quite burdened at the moment. They have more than enough on their plate, and they can't become occupational therapists or speech therapists on top of that.

So if the school system can't provide the therapy, then we need to start thinking outside the box about how we can loosen things up and perhaps find more ways to provide that.

1150

I pointed out Bloorview as an example. Although they only go to grade 1, that's an example of an environment where it is inclusive. There is some integration, but there is a lot of support by those alternative regulated health professions. They have speech therapists on staff; they have occupational therapists on staff. They work very closely with the teaching staff to implement things that each child needs. I'm not quite sure that that need really ends at six. I really think we need to see that continue forward and to develop programs that are closely modelled on that. That would be a huge benefit.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo?

Ms. Cheri DiNovo: Thank you so much, and I'm so sorry for what you've gone through. We're here to change that, we hope.

Ms. Rosanne Renzetti: I believe that.

Ms. Cheri DiNovo: Just very quickly, I particularly loved your suggestion—not the first, of course, that we've heard of a system navigator or caseworker, call it what you may, but someone who will walk with you from cradle to grave, as it were, develop plans along the way, that there be consistency rather than bureaucratic aspects of government that just administer assessment tests and then administer wait-lists. We don't need more of that. We need more direct help, and you have pointed toward that, so I thank you for that.

Ms. Rosanne Renzetti: Thank you.

The Chair (Mrs. Laura Albanese): And I want to thank you as well. We recognize and are fully aware of the frustrations you have been through. We want to try to improve that, and thank you for bringing forward really important suggestions.

Ms. Rosanne Renzetti: Thank you for your work on this matter. We do appreciate it.

FETAL ALCOHOL SPECTRUM DISORDER ONTARIO NETWORK OF EXPERTISE

The Chair (Mrs. Laura Albanese): Now we'll hear from the Fetal Alcohol Spectrum Disorder Ontario Network of Expertise, FASD ONE. Please take a seat.

Ms. Sharron Richards: Good morning, and thank you for allowing time for us to speak to you today. I'd like to just acknowledge our appreciation that we're in a tough time slot here. We're just following the very moving and powerful presentations of parents and we're in the pre-lunch spot, so we'll do our best to keep your attention.

I'm Sharron Richards. I'm the chair of Fetal Alcohol Spectrum Disorder Ontario Network of Expertise, which we're going to refer to as FASD ONE. A few years ago, I retired from close to 38 years working in child welfare and now I am involved as a community volunteer. I'm accompanied by my esteemed colleague Nancy Hall, who is the lead of our support and intervention action group. In her other life, she's a facilitator with the Southern Network of Specialized Care.

FASD ONE is a volunteer collaborative of caregivers, practitioners and specialists committed to the prevention of FASD and the development and dissemination of information that will support individuals affected by FASD and their families. Our members come from communities across Ontario, including First Nations, Métis and Inuit communities. I know that some of our members have appeared before this committee in other parts of the province.

Our presentation is going to speak to three aspects for your consideration: We're going to provide you with some background on FASD, which may be a repeat of what you've heard, and we apologize for that; we're going to talk about the human and economic costs of FASD; and then we're going to talk about the recommendations.

I'm going to ask my colleague Nancy to speak to the first two sections and I will speak to the recommendations.

Ms. Nancy Hall: Thank you, Sharron.

Background: As you may know, FASD is a brain-based physical disability with developmental impacts resulting from prenatal exposure to alcohol. It is an umbrella term used to describe the range of effects that may include physical, mental, behavioural and/or learning disabilities. You may also know that it's preventable. Because it is incurable, those affected will require a range of supports across their lifespan.

The Public Health Agency of Canada estimates that this disability affects approximately 1% of the population. While there have been no prevalence studies conducted yet in Ontario, it is estimated that it currently affects over 130,000 children, youth and adults living in our province. It is believed that the prevalence is under-

estimated. Three studies presented at the last international conference on FASD identified the prevalence rate as 2% to 5%.

Contributing factors to underestimating prevalence include the fact that FASD is often invisible, not understood and misdiagnosed, and for which there are few diagnostic services across the province that are accessible and affordable and, I would like to add, knowledgeable. An additional factor is the stigma associated with women drinking while pregnant, which prevents women from confirming prenatal alcohol use, a requirement for a diagnostic referral.

An increase in the prevalence of FASD can be anticipated with the development of increased diagnostic services and training for caregivers and service providers to understand, assess and screen for FASD, and because, according to Health Canada, 20% of women of child-bearing age consume five or more drinks at a time once per month or more often, a rate three times higher than a decade ago. Women at the highest risk of binge-drinking are 15 to 19 years of age, followed closely by those in the 20- to 24-year-old age bracket, all of child-bearing age. Health Canada estimates the overall rate of unplanned pregnancy to be 40%, with the highest rate, 82%, of unintended pregnancies among 15- to 19-year-old women.

FASD impacts the cognitive, mental, social, adaptive and executive functioning of those affected. As a result of their brain injury, people with FASD face a wide spectrum of lifetime challenges, from mild to very serious physical, mental and emotional disabilities. Throughout their lives, individuals affected by FASD will experience challenges such as:

- delays in meeting developmental milestones;
- memory problems;
- language comprehension, both verbal and written. They may have good articulation skills, but they may often not understand what they are saying;
- difficulties processing information, filing and retrieving it when needed;
- difficulties with abstract thinking and reasoning, so they hear, think and reason literally and concretely;
- inability to understand cause and effect, so they can't transfer learning from one situation to another;
- not picking up on social cues, causing them to relate inappropriately;
- poor regulation of their emotions and behaviour;
- poor decision-making, including in the relationships that they develop;
- poor time and money management skills;
- difficulties with planning, organizing and other executive functions;
- trouble maintaining appropriate attention and focus; and
- daily living difficulties.

A significant challenge for most individuals affected by FASD relates to the discrepancy between their chronological age and the age at which they function. We call this dysmaturity. In other words, they will function at a younger age than their chronological age in most areas

of their lives. The exceptions are in their communications skills and their sexual development. As a result, they appear more competent than their actual abilities, leading to high expectations from others and subsequent failure in meeting those expectations.

If not diagnosed early and followed by access to appropriate supports and interventions, individuals with FASD are at a high risk of experiencing additional challenges, including poor family planning.

When we look at human and economic costs, without an informed system of care providing appropriate supports and accommodations, the human cost for people affected by FASD and their families is substantial. Ninety-five per cent will experience mental health issues; 82% will not be able to live independently; 80% will be raised by someone other than their biological parent; 70% will have problems with employment; 68% will have disrupted school experiences; 68% will come into contact with the law; 52% will exhibit inappropriate sexual behavior.

For individuals affected by FASD, they experience a pervasive and persistent sense of failure and frustration, believing that no one understands their lived experience, that they are constantly a disappointment when unable to live up to expectations and because they are aware that others consider them to be different, stupid, weird, unwanted and difficult. They are the people who are socially isolated and disenfranchised from the civic life of our communities.

The burden borne by individuals affected by FASD should alarm us all and rally us to proclaim that these costs are unacceptable in a province as resource-rich as Ontario.

All Ontarians bear the economic costs of FASD when those affected significantly strain publicly funded systems of health care, child welfare, education, mental health, addictions, justice and social assistance. While the cost of FASD to the public is difficult to determine, it has been estimated as anywhere from \$1 million to \$3 million per individual over a lifetime, while \$5.3 billion to \$7.6 billion is estimated to be spent annually in Canada to support those with FASD from birth to age 53.

1200

Despite the considerable money being spent on services intended to support children, youth and adults affected by FASD, it is not producing optimal outcomes. They are often referred to as the service users for whom nothing works, but it will work when the disability is understood and when services are planned and delivered collaboratively to accommodate the disability. Service systems need to operate on the basis that service delivery must accommodate the disability, rather than expecting those living with the disability to accommodate the service providers or service systems. We have attached the FASD Peterborough key findings report, as it further addresses the accommodation issue.

It also needs to be noted that when service provision does not understand and accommodate the disability, the result is harmful and not simply benign, as it sets up

expectations for those living with the disability that they cannot meet. It results in everyone involved feeling like failures. I want to speak on the side: As a mother, I can certainly confirm that you definitely feel like a failure. You feel like you can't do anything right until you understand this disability, and it's the same for service providers. It's really critical. It results in everyone feeling like failures, which for those living with the disability becomes destructive and debilitating over the course of a lifetime. Understanding and accommodating FASD is about working differently and not necessarily harder, and it's about making better use of existing services and resources to achieve better outcomes.

Finally, approximately 10% to 25% of this population will meet criteria for developmental services. Given the mandate for developmental services to provide service to provincial crown wards before all others, along with what is estimated to be a significant prevalence of FASD-affected crown wards, it's important for the Ministry of Community and Social Services to recognize that the impact of FASD on developmental services is growing, and it needs to be addressed.

Ms. Sharron Richards: Our recommendations are founded on two critical factors: (1) that FASD is a preventable disability; and (2) that improved outcomes can be realized through early diagnosis and interventions that accommodate the disability and result in realistic expectations and optimal outcomes.

Our first recommendation is that the province of Ontario must engage with community stakeholders in the development of a provincial framework to address FASD. Ontario is one of the few provinces yet to develop an integrated approach to addressing FASD. Our network, FASD ONE, is in the final stages of preparing a document that we hope will contribute to the development of a provincial framework on FASD. Once completed, it will be presented to the provincial government for possible approval and implementation. We ask that this committee urge the government receiving the FASD ONE framework document to give serious consideration to its adoption, along with dedicated funding to implement the framework.

Second is that the province of Ontario dedicate resources to the prevention of FASD through public awareness, education and timely access to services for pregnant women using alcohol. FASD is a preventable disability. It is estimated that for every dollar dedicated to prevention, \$6 will be saved on reduced call on services that frequently go from the least expensive to the most expensive services. All Ontarians, but especially women of child-bearing age and pregnant women, must receive accurate information regarding the risks of alcohol use during pregnancy and have access to the services required to abstain from or limit alcohol use in pregnancy.

Our third recommendation is that every person in Ontario who is affected by FASD have equitable access to the range of supports and services they require to live successful and productive lives. Every Ontario resident living with FASD and their families will require lifelong

supports such as diagnostic services, respite, educational support, supportive housing, employment support, family planning, opportunities to become part of the social fabric of their communities, service providers in all sectors who understand their disability and lifelong case management services.

A recent study of youth with FASD living in Ontario found that 86% of youth had never been referred to or received any FASD-specific intervention or services, despite high levels of functional impairment across domains. Moreover, the majority of youth who had received specialized interventions or services had done so when participating in research.

Accessing needed resources and services shouldn't depend on where those affected live, in which service system they are being served, or whether their family can afford to purchase services for them. Eligibility criteria must be based on adaptive functioning and not just IQ in order to be inclusive of individuals affected by FASD. Equitable access to services should be considered their right.

The fourth recommendation: Capacity must be developed for the delivery of FASD-informed services in all systems and across all sectors. Regardless of which service sector one works in, an understanding of FASD as a brain injury with developmental impacts should be a practice prerequisite. Once FASD is understood as a brain-based neurodevelopmental disability, it should lead to two things: (1) an appreciation for the prevention of the disability through a message of no alcohol use while planning to become pregnant and when pregnant, and (2) for those currently affected, the critical need for early screening, assessment and diagnosis accompanied by early and appropriate interventions and supports.

Recommendation 5: It is critical that the Ministry of Community and Social Services prioritize identification of individuals with FASD as well as training and education in effective intervention approaches to create an informed system of care within developmental services.

Research clearly indicates that informed understanding and accommodation create positive outcomes for persons with FASD; therefore, screening, identification and training for all staff within the developmental sector is imperative for long-term success. The prevalence of this disability within the sector demands the development of expertise and specialization.

Number 6: Service system philosophies must make a paradigm shift from a goal of independence to interdependence. Many people living with FASD will not be able to live independently. Throughout their lives they will require support to help them manage the challenges associated with their brain injury. When they are served by systems whose goal it is to help them become independent, they will always fail to meet that expectation. For service systems to continue to have that as a service goal, it inadvertently places those affected by FASD in harm's way. It is in everyone's best interest to aim for interdependence with lifelong supports as a realistic, achievable goal.

Number 7: The child and youth service systems and the adult service systems must work to provide an

integrated, seamless transition from one system to the other. We know that transitions for those affected by FASD are difficult and challenging. When the transition from the child-youth system to the adult system is not smooth and integrated, as is currently the case, too many young people affected by FASD aging into adulthood fail to make that transition.

They also go from a system in which they may have received significant support to one that expects a level of independence they cannot achieve. Case management services for those affected by FASD, especially transitioning-aged youth and adults, are frequently identified by caregivers and service providers alike as a critical but almost non-existent service.

Navigating our systems of service is not easy for most of us, but is almost impossible for a person living with an injured brain that significantly impairs their functioning.

Number 8 and our last recommendation is that a lead ministry be identified to coordinate an inter-ministerial approach to addressing FASD. FASD involves several provincial government ministries: health and long-term care; children and youth services; community and social services; education; colleges and universities; community and public safety; and the Attorney General. Yet, there is no one ministry assigned the lead responsibility. This needs to change in order to move forward to better address FASD at the provincial level.

We thank you for your time and your attention. On behalf of FASD ONE and all those in our province who are affected by FASD, we applaud your committee for addressing the issue of improving services for residents living with a developmental disability. We look forward to seeing our recommendations, as well as those of all the parents and caregivers who have appeared before you, reflected in your final report.

Thank you.

The Chair (Mrs. Laura Albanese): And we thank you for your presentation—very insightful. There's no time for questions, unfortunately, but we really appreciate everything that you brought forward. Thank you.

Ms. Sharron Richards: Thank you and good luck.

Ms. Nancy Hall: Thank you.

The Chair (Mrs. Laura Albanese): Thanks. We're recessed until 1 p.m.

The committee recessed from 1210 to 1300.

MS. FRANKE JAMES

The Vice-Chair (Mrs. Christine Elliott): Good afternoon. I'd like to call the committee back into session this afternoon. Our first presenter is Franke James. Thank you very much for being here. You have 20 minutes for your presentation, and you can start whenever you're ready.

Ms. Franke James: Wonderful. Thank you very much. I have a really, I think, shocking story to tell you, but we're hoping that it has a happy ending. The role that you can play is to help make that happy ending. I've got specific suggestions at the end of my talk.

This is Teresa's story. It's about crisis, capacity and courage. I'm her sister Franke James. This is my sister Teresa. She's 49 years old and has Down syndrome. Teresa lived with my parents all of her life. After my mother died in 1999, she moved with my father to a condo in north Toronto.

On November 27, Teresa was admitted to a nursing home. We found this very odd because Teresa is an active, strong-willed and able-bodied adult. Teresa should never have been admitted to a nursing home. You can see in this picture her fellow patients, residents, at the Rekai Centre are in wheelchairs, and Teresa is doing her power walk.

The admission was done against her wishes. Let me just go back to that. I've blurred out the people for privacy reasons, but you can see that they're actually being fed. Teresa doesn't need anybody to feed her.

It was also done against the wishes of her father and me. How could this happen? The system did not protect Teresa. We're talking about the Griffin Centre, the CCAC, the Rekai Centre, Surrey Place, the DSO, the Toronto police and Family Service Toronto. In fact, the system actually worked against Teresa. Her human rights were taken away. Teresa's father lost his rights to protect his daughter. The CCAC crisis list was manipulated to put Teresa into a long-term-care home. Teresa's human rights were taken away.

When we look at this picture, we've got three bubbles: my father's, my sister's and a sibling's voice. Whose voice would you listen to? My dad says, "I do not want Teresa in a nursing home." Teresa says, "I want to stay in the condo." A sibling says, "Teresa should be placed in a nursing home."

On September 4, the CCAC assessed Teresa as not capable. They used Teresa's statements about her independence—"I shower myself"; "I dress myself"—as evidence of cognitive decline. The staffer Mark Weitz wrote, "The client has no insight into her dependency on others to shower her and dress." The client said, "I shower myself"; "I dress myself." So obviously they're believing the caregivers, and they're not believing Teresa.

The CCAC repeatedly ignored Teresa's stated wishes: "I like the condo. I want to stay in the condo. I like it here. I can play computer and watch TV." This is from actual files that we've obtained from the CCAC, and they were very difficult to obtain.

The CCAC ignored their own observations about Teresa. This is how the CCAC worker described Teresa: "a pleasant, calm and quiet client with Down syndrome who enjoys close relationships with her family members and at her day program at Addus."

Teresa's father lost his rights to protect his daughter. How can that be? The CCAC learned from my siblings that Teresa's dad, the senior power of attorney, would oppose Teresa's placement in a long-term-care home.

I'm just going to read this little bit to you that's highlighted in yellow: "Joseph, who is likely primary on the power of attorney document, would be upset regarding

the client being placed in a long-term-care home. The DCC agreed to meet the client at Joanne's address"—that's one of my siblings—"so as not to upset Joseph. Joanne said she's pretty certain Joseph would not challenge the authority of secondary attorneys, and the DCC has suggested that the client could possibly make another POA document, though this will need to be discussed in more detail later."

The CCAC suggested on September 6 that Teresa's dad could have his rights removed. So, as a sibling, I am just shocked that the CCAC is advising how to remove my dad's rights. It's unbelievable. This is probably one of the most difficult and horrific episodes in my life.

"The DCC said that if Joseph asserts his right to be primary attorney for PC and will not address the issues involved in the client's increasing need for care, this shows inability to respond in clients' best interests and that a form G submission to the CCRB may be necessary." So they're giving advice on how to remove my dad's authority. My dad is a former lawyer, a QC, and a war veteran.

On September 10, CCAC interviews Teresa's dad and notes that he very clearly does not want Teresa put in a long-term-care home. "Joseph is adamant he does not want Teresa placed in a long-term-care home and became somewhat litigious, saying, 'I stopped practising law a few years ago, but I'm able to get a lawyer if I need one,' and that he would fight attempts to place client in a long-term-care home."

On September 11, the CCAC receives revocation documents removing Joseph Pocock's power of attorney. So my siblings, without telling me, without telling Teresa, without it becoming a known family issue, removed his rights as power of attorney over Teresa.

"DCC received a copy of a letter showing client's father Joseph Pocock has resigned as of 2013 September 8 as attorney for personal care. Now the siblings William and Patsy will take over care."

The CCAC, interestingly, did not question the revocation document. It's really curious that they didn't, because it was legally invalid, because it was signed by the spouses of the attorneys. So as Teresa's sibling, I am furious that my brother-in-law and my sister-in-law signed this document without my knowledge that took away my dad's rights to protect my sister.

That's another shot of it.

The CCAC crisis list was manipulated over and over again to put Teresa at the top and into a long-term-care home. On August 23, Teresa was falsely described as incapable of taking care of herself. It says that she needs physical assistance for bathing, for personal hygiene. She even needs physical assistance for the toilet, to wipe herself. She needs physical assistance to dress her lower body. This is not the sister that I know, and I am shocked that this would be in the CCAC's records.

1310

On October 5, Teresa was described as having insidious cognitive problems and decline: "Client has

Down syndrome, insidious onset over past year of short-term memory and procedural memory loss with accelerating STM loss/confusion over the past three to six months." Personally, I think that this was engineered in order to qualify her for a long-term-care home and it was a figment of my siblings' and the CCAC's imagination.

On October 5, Teresa was reported to have had wandering events: three, possibly more, wandering events in the past six months. So they're stacking the deck to make her qualify for a long-term-care home.

Mr. William James: Like Alzheimer's.

Ms. Franke James: Like Alzheimer's.

On November 21 and 22—so we had emails going back and forth amongst the siblings. When I really realized that they were serious about putting Teresa in a nursing home, I went, "Well, this is ridiculous. You can't put her in a nursing home. We are willing to take responsibility for her. Teresa's happiness is the most important issue here. We will be contacting the DSO to let them know we are willing to take Teresa and require further information about her health."

However, my siblings refused to give us any information about her health, and on November 27, Teresa was admitted as a long-term placement to the Rekai Centre. This was done with deceit and trickery. Teresa was taken out for a nice breakfast and then, instead of going to her program at Addus, she was taken to the Rekai Centre.

This is my brother speaking: "Colleen," his wife, "and I met Teresa this morning at the condo, went out for a nice breakfast and then went to the Rekai Centre at 10 a.m. Patsy," another sibling, "and her husband, Gerry, packed up what Teresa needed and met us there on our arrival." This was done without Teresa's consent and without my father's knowledge and without my knowledge.

"Patsy and I went over to the condo this afternoon to let Dad know what was happening. Dad was not pleased. He said he no longer has a reason to live on," and we'll see more of this.

November 28: CCAC was informed about my offer to take Teresa. On November 28, my lawyer contacted the CCAC. So they knew that I had offered to take Teresa. That should have taken Teresa off the crisis list and that should have taken her out of the long-term-care home, but it didn't.

On November 30, my dad, my husband and myself went down to the Rekai Centre and Teresa was discharged under the authority of my father, who was senior power of attorney. We had not seen the revocation document and they didn't have it on file. We didn't know anything about it.

On November 30, I spoke with the CEO of the Rekai Centre, Mary Hoare, and told her about my offer to care for Teresa. On November 30, the CCAC, unbeknownst to me, suggested calling the police to return Teresa to the Rekai Centre. What is going on? I mean, how could they be doing this in good conscience?

The CCAC writes, "If the client is at risk, the daughter," meaning my sibling, "can call the police to see if there is anything they can do to assist."

That night, the police arrived at my dad's home and took him, against his wishes, to Sunnybrook Hospital under a form 2, Mental Health Act, allegedly for being suicidal. I don't think it was anything to do with being suicidal. I think it had to do with the fact that my dad was threatening to change his will, and he was taken to the hospital instead of having the opportunity to meet with a lawyer. He was released later, in the early morning hours of December 1.

On December 1, the Rekai Centre was informed again about my offer to take Teresa. I wrote to Mary Hoare, and I said, "Thank you for speaking with me yesterday about my sister Teresa Pocock and her discharge from the Rekai Centre." I can give you copies of all of this, so you can read it in detail. I'm just going to read this quickly. I put this in writing to my siblings again—December 1. We had Teresa at our house, and I said, "Bill and I want Teresa to live with us. We feel it would be ideal for many reasons. We have an extra bedroom. We work at home. Our schedules are flexible. She will be close to family members, and she will be in the same neighbourhood she grew up in. We feel we can help Teresa to grow and develop to her full potential, as we have helped Teresa to develop her ability to do walks, such as the eight-kilometre Terry Fox walk. Our ultimate goal will be to have Teresa at a group home, if that is eventually what she wants and is in her best interests. But we are in no rush. We would be honoured to have Teresa live with us. Please let us know if you support our decision."

On December 4, we got a knock at the door. Three big policemen had arrived, after a missing persons report from the Rekai Centre, to take Teresa back to the nursing home. It makes me angry and upset to go through this again. So there I was, showing the policeman the documents, the photographs—I am a photographer, I'm a videographer; we documented all of this. We worked with a lawyer throughout this whole process. Fortunately, the police agreed—and I think it was an hour and a half I had to go through all of the documents and show them the video that we had taken, that Teresa was safe. They allowed her to stay with us.

On January 6, the CCAC, Surrey Place, refused to release Teresa's medical records, saying that Teresa's capacity was in question.

On January 11, Teresa had a new capacity assessment and was found to be capable. This is so important. Teresa Pocock is capable of granting a power of attorney for personal care. Kathy Sullivan, who has been a capacity assessor for 40 years, met with Teresa in our home on two occasions. She could see that Teresa wanted to live with us and wanted us to help her make her personal care decisions.

On January 15, Teresa signed a new power of attorney for personal care, and this was with her lawyer, Jane Martin. Teresa had never had a lawyer before, but she does now, and it's not my lawyer; it's her lawyer.

On January 18, Teresa got her CCAC records, and you're seeing some of them here.

Now I'm going to show you some photos of how Teresa is thriving at our house. You see she's wearing oven mitts and holding a lasagna that she has helped to make. She's at a Christmas party at Addus. Teresa is doing her happy dance. Teresa is thriving.

Even during the power blackout in Toronto, we managed to get away to a family's place that had power, up in Collingwood.

We are honoured and happy to have Teresa live with us, but it has been a horrible, horrible experience that brought me here today to tell you what has been happening.

I just want to go through our recommendations.

(1) The consent and capacity law is easily abused, so we need to change it. It appears that we have no recourse to hold our siblings, but most importantly, all of the organizations that worked against Teresa, accountable. We'll be exploring that in more detail, and maybe you can advise us. But our lawyer has told us the consent and capacity law needs to be updated.

1320

(2) The crisis list is broken; we need to fix it. If you go through all of the documents and the emails leading up to this, you will see how the description of Teresa was manipulated and changed in order to make it sound like she couldn't take care of herself and she had to be in a long-term-care home. I have never helped Teresa in the toilet. I have never helped dress her. She does not need help bathing, but I do supervise her to make sure she gets in and out of the tub safely.

(3) The disabled and the disadvantaged people are getting hurt in Ontario's care system, and we need protection for them. Nobody would know about this; Teresa would still be at the Rekei Centre if I had not stepped forward, with my husband's help, to get her out of there, and it is really, really shocking.

That's my presentation. Thank you very much.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much, Ms. James. I think I can speak for all of us on the committee when I say that this is a truly shocking story that you have told us today. I'm so sorry that you and Teresa and your family have had to go through this. We absolutely will take everything that you've said into consideration.

I'm wondering, if it's all right with Teresa—because they're her records—if she would consent to your allowing us to have a copy of them. I think we'd all like to really understand a little bit better what went on here so that we can make the necessary moves to effect change.

Ms. Franke James: That would be great. As her power of attorney—and my husband is now power of attorney—Teresa, is that okay?

Interjection.

Ms. Franke James: Okay. The other thing I'd like to say is that if you would like a printed copy or a digital copy of my presentation, you're welcome to it. There are other background documents that I can provide, as well, which substantiate everything I've said.

The Vice-Chair (Mrs. Christine Elliott): Yes, if you could provide us with all of that information, I think we

would all be most interested in receiving it and reviewing it.

Unfortunately, we don't have any time left for questions, but I'd like to thank you very, very much for being here today and sharing your story.

Mr. Bas Balkissoon: Just a quick request: If your lawyer can send us any information on the law and a suggestion—because we heard the same complaint with the mental health review. Three of us who were on the committee would love to hear his opinion.

Ms. Franke James: Our lawyer is Brendon Pooran, whom you may be familiar with. He's on the Consent and Capacity Board. He has been a tremendous help for us throughout this.

Mr. Bas Balkissoon: We'd love to hear what he would suggest.

Ms. Franke James: That's great. Thank you very much for this opportunity to present.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much. I'm glad this story had a happy ending, at least.

The Vice-Chair (Mrs. Christine Elliott): Ms. Wong?

Ms. Soo Wong: I just want to say thank you for sharing your story and thank you for fighting for Teresa. This is what it's all about.

I do have a question, Madam Chair, for the researcher.

The Vice-Chair (Mrs. Christine Elliott): Yes?

Ms. Soo Wong: I am in shock right now to hear about the CCAC.

Is it the Central CCAC?

Ms. Franke James: It's CCAC Toronto.

Ms. Soo Wong: Okay. I want to know whether it is the Toronto LHIN—because the CCAC reports to the LHINs—I want to know the rights and abilities. Because if it happens in the Toronto CCAC, how many other CCACs are currently in a similar situation? I want an explanation, given the consent we just received from Teresa as well as the POA, of how this could happen.

Coming from the health care sector, the rights of the POA are supposed to be respected, and the law is there to protect those rights.

I need some clarification from the LHINs—because very, very clearly, there's a chain of command here, and I'm concerned. If it happens at the Toronto CCAC, other CCACs across the province are in a similar situation, where the wishes and the choices of the POA are not being respected. I just want to ask the researcher to go back and find out about the CCAC and get some information for the committee.

The Vice-Chair (Mrs. Christine Elliott): Ms. Wong, we should probably review the background first, so that we really understand the issues, and then we can go back with very specific questions to the CCAC, if that's all right with you.

Ms. Soo Wong: Yes, okay.

Mr. William James: Can I make a simple comment on that? I think the problem with the CCAC is that there is a conflict of interest with the people who are serving the clients and the powers of attorney. The client was

Teresa, and another client was Joseph Pocock, her father, but the person working for the CCAC was serving the powers of attorney—

Ms. Franke James: The secondary ones.

Mr. William James: —the secondary powers of attorney, and was working to serve their needs. Because of that, they didn't really think about Teresa's needs or her father's needs, so that's the conflict of interest there. There needs to be something to help people separate who they should be taking care of, because, certainly if you read all of the documentation, the primary directive is always to serve the client first. That is the official policy, but it just wasn't done.

The Vice-Chair (Mrs. Christine Elliott): Clearly not. There is a clear delineation of legal authority there that, it appears, was undermined significantly in this case. We will certainly look into this, and we will look forward to hearing from your lawyer with respect to specific suggestions.

Yes, Ms. DiNovo?

Ms. Cheri DiNovo: Yes, just quickly: We heard in Ottawa from a group called People First. Their slogan is "Nothing about us without us," so I would definitely suggest that you hook up with them, because with that slogan, that says it all. It's got to be Teresa's wishes first.

Ms. Franke James: That's right. That's why Teresa is here today.

The Vice-Chair (Mrs. Christine Elliott): Thank you very much again for joining us.

Ms. Franke James: Thank you. And I will follow up—I suppose with Trevor—to find out how to submit those documents to you.

The Vice-Chair (Mrs. Christine Elliott): Great. Thank you.

MR. MITCHELL FEINMAN

The Vice-Chair (Mrs. Christine Elliott): All right. Our next presenter is Mitchell Feinman. I'd like to ask you to come forward, please, Mr. Feinman.

Mr. Mitchell Feinman: Does it matter where I sit?

The Vice-Chair (Mrs. Christine Elliott): Anywhere on this end, please. Thank you, Mr. Feinman. As you've probably heard, you have 20 minutes for your presentation. If you don't take up the entire time, we will have time for questions, so please start whenever you're ready.

Mr. Mitchell Feinman: Great. Thank you, everybody, for inviting me today. I'm so excited to be here. I thought what I'd start with is the letter that I wrote to the committee to get me the invitation today.

"Dear Mr. Day,

"I have been teaching students with developmental disabilities, including autism, in the Toronto District School Board the past 33 years, and I am so pleased to read about your upcoming meeting of the Select Committee on Developmental Services.

"I would certainly like to make an oral presentation to the committee in regard to the urgent need for day pro-

grams for young adults ... that reach the school-leaving age of 21 and are in dire need of services.

"The problems encountered by parents of young adults with developmental disabilities ... are complex and difficult to resolve. Difficulties faced by the families are increased rather than diminished by the physical maturing of their children. Parent respite and day programs could help alleviate some of the more serious problems observed: stress, fatigue, and irritability as a result of the strain involved in caring for their children.

"Many parents have their children on waiting lists for group homes, however, in the interim, need community support to help cope with the pressures of daily life.

"I have taught and know many students with developmental disabilities who have left the school system at age 21 and are now languishing at home with no available services while waiting for scarce placement openings to become available.

"Many of the achievements and gains my students have made over the years during their school career fade away due to the lack of further training, stimulation, retention and review once they transition from the school system.

"Young adults with developmental disabilities ... need to continue their education and gain more independence.

"Countless reports and recommendations have been presented over many decades by various ministries highlighting the shortage of services for adults with developmental disabilities.... There have been many recommendations in the past calling for innovative funding mechanisms such as public-private partnerships to be developed in order to create much-needed day programs for students who reach 21 years of age and must now leave the school system.

1330

"I am rapidly approaching my retirement and plan to intensify my efforts in securing and providing high-quality low-cost effective programs to individuals who are difficult to serve.

"I was previously granted a leave of absence," with pay, "from the Metropolitan Toronto School Board ... to undertake a study of the need for and the development of a highly specialized recreation-vocational-socialization learning centre for adolescents and adults affected by pervasive developmental disorders, particularly autism.

"I would love this opportunity to meet with the committee to discuss my project ideas and plans and how we may proceed to provide top-quality cost-effective services for individuals who require a high level of care and supervision....

"Thank you very much for your consideration.

"Sincerely yours."

That was the background for the invitation today, and now I'd like to say—sorry for my over-reliance on the use of cue cards and a script, but when I found out my every word and action was going to be recorded, I thought that this would be the best way for me to proceed.

The parents of students graduating, as has been said, have had an extremely difficult time in the past accessing

services that are appropriate for their children. The Toronto Star wrote quite a series of touching articles last year highlighting the problem. It totally inspired me to start working on the Bridging the Gap project again.

Over the years, I've been developing ideas to improve the coordination of services regarding the transition of graduating students. I've also served as a volunteer on the board of directors for the local Toronto chapter and the provincial branch of Autism Ontario, a provincial parent organization. I've attended eight annual information fairs that the DSO operated for families in Toronto, and this past May it was announced to families that Passport funding has been frozen at the current time, leaving some parents in tears.

I'm here today to talk for the thousands of students who can't speak for themselves. I thought I would talk a little bit about what is happening to my particular students who have graduated and have left school—regression, in most cases. Many of my students have become aggressive again: hurting, scratching, pulling hair, biting. Some are running away in the community from their caregivers. Some have lost their ability to speak or copy sign language words through a lack of practice. Some are no longer following instructions from their parents; they've become very non-compliant. Many have no access to computers or to tablets like an iPad, which is being used in classrooms so successfully. Many individuals at home today have never used or benefited from one of these devices. Some of my children no longer have use of or access to a voice output communication aid or a mobility therapy ball for physical exercise that they would have in a structured program like a school.

No longer having opportunities for appropriate social interactions, some of my students have become very obese from sitting on the couch and eating and watching TV all day. We've had increased rates of self-stimulation: repetitive behaviour such as rocking, watching finger movements, bouncing up and down on their couches all day, breaking them. Some of my children rip fabric at home all day. They are no longer going out in the community. They're not going to supermarkets and parks. The parents are embarrassed by their unpredictable behaviours. They are sometimes not able to deal with the behaviour. They may have to call their siblings to help deal with the temper tantrums, the terrible problems they have, while the parents are getting older at the same time.

I sat on identification/placement/review committees for 10 years at McCordic school when I was starting out, and I knew I had to do something to try to help get services at that time. I can't help but wonder why we spend so much time as a society educating these children if we don't care what happens to them when they reach 21. Parents and children need more support.

Ideally, I would now like to see the position of a transition coordinator created in the school boards in Ontario to help, and that's the page in the package that I gave out on the left-hand side. Also, I was thinking that perhaps a case coordinator should be appointed for each

student, to be responsible for their transition. As well, I think we need to follow up on the many students who have already graduated and are, as I say, languishing at home with nothing to do to occupy themselves. There are thousands of people in this province like that now.

I would hope that sufficient funding is allocated to the DSO agencies so they never have to tell a parent that the government money is frozen and they aren't able to help right now. I think, as a society and local community, we should feel fairly disappointed in the way we've been treating this population for so many years and continue to do so, although with meetings like this yesterday and today, hopefully we're getting better. I've researched and read many reports and articles written over the past 30 years indicating the same lack of resources for students with autism and other developmental disabilities once they leave the school system. Now, after all these years, we find ourselves in an "urgent" situation. I hate to tell you, but it's been urgent for more than 30 years.

Hopefully, something positive and wonderful will come from these meetings, I'm sure. I want to hope that things are going to improve and I want to give hope back to the families who may have lost theirs. So I feel a little different today, coming here. Most times, people approach the government for money and other assistance, but I'm here today to offer my assistance to the government. I don't want anything other than a chance to make some of these plans happen.

We have to learn how to manoeuvre the government system for parents; it's too unwieldy. I look at the trouble I have as a professional, and I just wonder how parents ever deal with it. You know what happens? They don't. They quietly endure and suffer rather than complain and fight. It's especially difficult for many of my families who have English as a second language to advocate successfully.

So I'm here today to share my plans that I've done over the past 29 years that will hopefully improve the lives of many individuals and their caretakers. I was granted, as I said, a half-time leave of absence with pay by the board to undertake a study on the need for and the development of a highly specialized recreational-vocational-socialization learning centre for adolescents and adults affected by pervasive developmental disorders, particularly autism. I decided to wait until I was ready to retire before leaving my teaching career to do this, and now that time is approaching. Hopefully, the benefits of such a program will be self-evident and people will support it so that it will grow. My plan is to continue building up my network of individuals and eventually bring them together.

So those are my prepared notes.

You have a sheet, "Proposed Summary of Duties for a Transition Coordinator for School Boards." They would be to support the team to facilitate the development, implementation and monitoring of transition plans for students with complex behavioural needs. I was thinking it would be great to have a transition office where the parents can come and find out about what services are

available from the school board perspective, working in conjunction with the DSO, which does some of this work. Right now, the school boards give a pamphlet saying, "These are the agencies that will look after over-21. Contact them and get your child on a waiting list many years in advance." But I was thinking it would help families if we had an office and maybe had videotapes where they could see some of the centres that are out there without having to go to the trouble of visiting all of them, so they could see which ones are of interest, narrow down their selection and maybe save some time and help them.

You can read most of the duties yourself on here.

As well, one of my ideas: While we know there are so many children waiting, why can't the school boards open up a classroom where people could drop in and have some socialization? We had that many years ago. The Toronto board did it for two years for 21- to 23-year-olds. But they found out the funding was a problem. The space was a problem: If we don't let the children leave the schools, where will the new ones go? So it was discontinued after a couple of years, but again, I would like to see a place where families could just bring their child in for a few hours to get them out of the house.

1340

That was my idea for the transition coordinator.

I prepared two pages. On the right-hand side of one is a summary of some of my original BridgeGap goals and objectives for the centre. I have a much more detailed binder that I didn't photocopy, but I could provide that to the committee if you're interested in seeing that.

As well, on the other sheet I have an overview of the different organizations, ministries and people that I'm now targeting to help me try to come up with the centre. Again, I'm just approaching them as an individual. This will be my approach to trying to get services.

I thank the committee so much for having me here today.

The Chair (Mrs. Laura Albanese): Thank you. We have about a minute of questions each. Ms. Jones?

Ms. Sylvia Jones: Thank you for your presentation. I have to say that we are told that the school board is actually in charge of transitions. With what you're presenting to us today, from working in the system, you're reinforcing what we've already heard, which is that we're doing a pretty crappy job of the transition, post-21.

I'm wondering if, instead of a transition coordinator, you have thought about a system navigator which would not be age-specific—so it's about navigating right from diagnosis, as opposed to this hiving off where we say, "The educational system is going to look after you from five to 21, maybe, and then someone else after that."

Mr. Mitchell Feinman: I wonder if a person would have the skills to know enough about the post-21 programs to advise the parents, if they have to know all the services right from nursery school on—to be such a generalist. Certainly, there is a need for that.

Ms. Sylvia Jones: Right now, there isn't much available post-21, so there isn't a lot to learn, but I hear you.

Mr. Mitchell Feinman: No, but there are so many people who are trying so hard, with the few agencies out there, to give them continued support and to expand their support—it's a fabulous job, in most cases.

The Chair (Mrs. Laura Albanese): Ms. Taylor?

Miss Monique Taylor: Thank you so much for all of the efforts that you put into this sector, and we can definitely see that you do that with a lot of heart and compassion. It's important, because we can never have enough—the last presenter hated the word "advocates." It's true; it's unfortunate that we need advocates, but without them, we would definitely not even be as far as we are, which isn't very far at all.

A system navigator is something that we've heard about quite often at this table—people who need to be in those transition roles to make sure that families have smooth transitions to get through difficult times in life. We've heard it quite often that families are getting over one hurdle, almost having time to catch their breath, before they're heading into the next hurdle of life, so we do really need to see those transition pieces in place.

Thank you for the work that you're doing, and keep up the good work.

The Chair (Mrs. Laura Albanese): Ms. Wong?

Ms. Soo Wong: Thank you very much for your presentation.

One quick question: Can you share with the committee, maybe not in the presentation—you can follow up with a submission to us: What is the TDSB doing with respect to the transitions for those—planning work with the parents of those who are currently between 17 and 21 years old, preparing them for the world outside the TDSB? If the TDSB is responsible for transitions, what programs, what services—who is leading that transition? I'd like to hear back from you, to this committee.

Mr. Mitchell Feinman: Okay.

The Chair (Mrs. Laura Albanese): Thank you for presenting to us this afternoon. It was very interesting.

Mr. Mitchell Feinman: Thanks again for having me. It's my honour.

CANADIAN ASSOCIATION OF MUSLIMS WITH DISABILITIES

The Chair (Mrs. Laura Albanese): We'll now welcome the Canadian Association of Muslims with Disabilities. Good afternoon. Please take a seat and make yourself comfortable.

Ms. Rabia Khedr: Thank you. My name is Rabia Khedr. I'm the executive director of the Canadian Association of Muslims with Disabilities. I am a person with a disability, who is also a sibling of adults with intellectual disabilities, as well as somebody who has been heavily involved from multiple directions—as a researcher and a trainer—in the developmental services section around diversity and inclusion etc., and, of course, as an advocate.

I appreciate the opportunity to have these 20 minutes to speak to you. I'm hoping that I leave you with some-

thing—now, why isn't my computer talking to me? Give me one second. I'm wired, just in case you're wondering. I have to have this little voice talking to me so I know what I'm talking about here.

What I'm hopefully coming with today is, I've provided you a five-page document there which has the key discussion points outlined, which I will go through, as well as an article attached as an anecdotal piece, a case narrative of a news article that was produced in the *Ottawa Citizen* on July 15, 2012. There is still no place for Mohamed. He sits in an ER today in Toronto, in fact.

Let me start by saying that families are generally very grateful. We appreciate the fact that there are so many services available to us in Ontario. We acknowledge the fact that there is no better place for people with disabilities to live a full lifestyle in any other part of the world but right here at home in Ontario.

Given that fact, we're grateful. We thank the system. We certainly value the efforts of the province to address gaps and appreciate the fact that this committee has been set up, and the fact that the Ombudsman's office has been investigating the sector. We are certainly looking forward to how transformation fully comes to fruition.

We appreciated the DSO when it was implemented. I actually even provided training around cultural responsiveness to one of the DSOs as it was developing, before opening its doors, and reviewed the support intensity scale application process to ensure that it was, in fact, addressing culture and spirituality and looking at an individual from a holistic perspective.

We really want to see consistency across the board in the sector. We want to see improvements because, as the population ages, as we've gone through these 30-plus years—as the teacher earlier was remarking on—between deinstitutionalization being finalized and community-based service being experimented with, we've come full circle through a generation of people's lives that have in fact fallen through the cracks.

My brothers are two of those individuals, today 36 and 38, who have certainly fallen through the cracks when education was just beginning to include them and the community was not ready to include them after age 21. I was told, "There's a big black hole," and I'm surprised that 20 years later I still sit here and there's a big black hole for people with developmental disabilities. That was the lingo we had out in Peel region: After 21, there's a black hole. There's nothing out there for these young men and women.

When I sat with a number of people, including ministry and service providers, and I said, "Really?", they said, "Yes." I said, "Does that mean I have to create something?", and they said, "Yes." I said, "Okay, I will." I formed a family group called Opportunities Mississauga for 21 plus. That's what they call themselves right now, but originally they were called—coined in my basement—925421+, because what else do adults want? They want something to do between 9 and 5, whether it's paid or unpaid.

Not much has changed. I'm basing some of the talking points here on case narratives and, like I said, the case in

point that I've attached. We really need to work toward improving the quality of life for Ontario's most vulnerable citizens. People with developmental disabilities are in fact the most vulnerable because they cannot voice their needs for themselves. Every one of us, including myself, will manipulate or play around with their interests, whether we like it or not, because we're all impacted through facilitating support, so we will always try to get the upper hand. One sibling, one parent, the other parent, community will always have their own agenda behind the provision of care, so I'm really not even sure how we can guarantee absolute justice to this particular population.

1350

However, looking at navigating the developmental services system, certainly, diverse families lack service literacy, face language barriers and have challenges accessing the system. When somebody like myself, who has participated in the system from many different perspectives, has challenges navigating it, I can just imagine if people have barriers.

Case loads and burnout certainly limit the quality of service that is provided to families by front-line workers. Some of them have grown up in the system. Enough is enough—okay, my sarcasm is kicking in; I apologize. But in all fairness, after a while, when you have nothing to offer, it becomes very difficult to serve families, when all you can say is, "We have nothing to offer." Unfortunately, what ends up happening is when families are presented with options that don't meet their criteria, families like mine are made to feel like, "Oh, well, we're giving you something. You should be grateful."

The DSO layer, in fact, we had great hopes and dreams for, but it has complicated the system at present, and we're not sure exactly why that is. It has added an extra layer, which really hasn't brought about sufficient change. Perhaps, case in point mentioned previously, frozen resources are part of that problem.

Service gaps: A big, huge part of what families need that has not been present from the get-go is access to some sort of counselling or intervention through social workers to help them truly understand the nature of their child's disability, to bereave through it, because there is a bereavement dimension. Let's be honest: I don't want to have a blind child or a developmentally delayed child. I will feel badly for that. As somebody who's an activist, I can very confidently say that. We don't pray for that. If it happens, okay, thank God, I'll do my best. But it's not our first choice. Every parent, every human being looks forward to a healthy, "normal" child, whatever normal means. So there is a bereavement dimension to that that families usually don't even have an opportunity to cope with over a lifetime. They need to develop coping mechanisms; they need to feel that they're not alone. They need to really learn to put that into context and then move to the planning stage, because there is a lifetime of planning that needs to happen in order to ensure appropriate care—self-care and care for the person receiving care.

We certainly see that service providers lack competence in serving diverse families and addressing their spiritual and cultural expectations. There are regional disparities from city to city and town to town in terms of how services and programs are actually delivered at the front line. An inclusion philosophy is not implemented in practice, although agencies are bound by it in essence. Families in crisis find inadequate supports although there are crisis networks. Again, there's conflict of interest on those crisis networks because they're made up of the very agencies that the families might be challenging in terms of service delivery to intervene in a crisis situation.

Individuals with complex needs and dual diagnoses fall through the cracks. They have limited access to appropriate supports, and that includes the whole range of supports required, from medical to social to recreational to educational—the whole gamut of services, whether it means even down the criminal stream. Often they are falling through the cracks. If developmental services isn't prepared to pay for the services that they need, the government is paying for services through either the criminal stream or the health stream. Somebody is paying when people fall through the cracks because there is a need in crisis situations for intervention, and people are turning to EMS etc.

These streams of health, EMS, emergency rooms and hospitals are inadequately equipped to support people with developmental disabilities and, in fact, violate their human dignity.

The example I can give you is: My brother was taken, time and time again, by police to the local hospital. In the mental health room, he would be kept in ER to the extent that, because he wasn't comfortable there, he was acting out, his drugs were out of whack, they had him sleeping on the floor on a mat and stripped down to nothing. That's not human dignity, as far as I'm concerned. Every human being deserves dignity, no matter what kind of situation they find themselves in.

A two-tier system provides inequities across the board between families and individuals in terms of supports, whether families are accessing residential services versus families in the community providing care.

A series of recommendations to put forward:

We need to reframe provincial and national values to balance fiscal responsibility with our moral and ethical obligations to provide basic human dignity to our communities' most vulnerable.

We need to ensure that we are, in fact, complying with provincial, federal and international law, when it comes to our legal obligations, through a range of flexible services.

We need to do a province-wide review of the implementation of the DSO model through a third party to really see where we're at three years later.

We need to also pursue new and innovative partnerships and invest in initiatives with family and community groups, with new and emerging groups with new ideas, to foster creative solutions and involve everybody to invest and share and put hand in hand to ensure that there are

programs and services, day programs etc. available to people with developmental disabilities in their local communities. That can be done through, again, asset-mapping etc. We need to bring new assets to the table, with government support.

We need to review layers of bureaucracy within the sector in order to ensure that dollars are applied to direct service delivery, not just invested in top-heavy processes.

We need to redefine the case management function to provide greater support to families. We need to mandate system-wide training to ensure that service delivery is culturally responsive and develop anti-racist, anti-oppressive practices throughout the sector.

We need to promote system-wide recognition of family caregivers.

We need a comprehensive aging and developmental disability strategy, given some of the issues that we've already heard and I'm sure you've heard around people being placed in nursing homes etc. age-inappropriately and needs-inappropriately.

We need to break down barriers between ministries. The anecdotal piece, again, around this that I can use is access to CCAC services versus developmental services. My 36-year-old brother was grandfathered into the CCAC program because he received home care and respite through them. This service has been accessed by him for a good 12 to 15 years now, I think.

There are multiple layers. You have the Ministry of Health, you have the LHIN, then you have the CCAC, and then you have the service agency. But the real relationship is between his family, his worker and him. Really, I think there's just so much streamlining that can happen there. I think you get my point. So we need to break down barriers and provide flexible services.

We need a provincial task force to address service gaps for individuals dually diagnosed, and do an environmental scan of successful models. One of the most successful models, in my experience, has been CWSDS—their STATE program and their dual diagnosis team and their one neurodevelopmental psychiatrist, Dr. Jay Rao, in Ontario, who is the only medical professional who actually understands developmental disabilities with the utmost dignity, coupled with any other issues, whether it's mental health or behavioural etc.

1400

We are, as an organization, as individuals, committed to building capacity through diverse communities to ensure that we develop new support models, and we welcome further engagement to address service gaps.

I've also provided you the story of Mohamed. The headline was "No Place for Mohamed." Mohamed catches headlines, I guess. He's a high-needs gentleman who has fallen through the cracks, with a developmental disability, with other multiple issues. He was hospitalized; \$1,000 a day was the price tag pinned to that. He still has no permanent placement. Since then, he relocated to Peel and was inadequately served at the local hospital and was sent down to Toronto Western. He is presently again in complex care.

His behaviours are criminalized because when he has seizures, because they're unresolved, he acts up in the situation of a seizure. He is a black man who is often charged with being aggressive, so mom has to fight multiple battles, not only trying to access appropriate health care to save her son's life at the moment, but to deal with the criminal justice system to try to explain why he is not criminally responsible for his behaviours, that his behaviours are the outcome of a crisis situation coupled with mental health, brain injury and seizure disorder.

I don't know what else I can say. I can talk for a day to you folks with my lived experience and advocacy work that I do. All I can emphasize is that the system is badly broken. We have the best of intentions, we are doing our best to patchwork, but families are falling through the cracks. People are struggling in their day-to-day lives, they're feeling isolated, they're feeling alone. We really need to invest in bringing families together, communities together, trying a new way of doing and knowing what needs to be done in the system and engaging new and emerging communities and groups and individuals who have new drive and passion. Thank you very much for your time.

The Chair (Mrs. Laura Albanese): Thank you for your thorough and passionate presentation. You bring forward some different points of view. Unfortunately, we don't have time left over for questions. However, we will take this into serious account, and should we have any further questions, we will make sure to contact you. Thank you very much for coming here today and presenting to us. We really appreciate it.

Ms. Rabia Khedr: Thank you.

Ms. Angela Bach: If you wanted to ask questions—I'm next in line—I don't mind if she encroaches on some of my time.

The Chair (Mrs. Laura Albanese): Are there any questions from the members? Ms. Jones.

Ms. Sylvia Jones: I'm going to ask one question because you're the only presenter so far who has said don't get rid of the DSO; study it for three years. I guess my concern is—

Ms. Rabia Khedr: Not study it for three years, no, no, no. It's been three years.

Ms. Sylvia Jones: My question is, if we review it, that money can't be diverted, channelled somewhere else. What do you see in the DSO that you think could work that is not working?

Ms. Rabia Khedr: When I was first introduced to the DSO, the support intensity scale etc., I found it very helpful. I know many families find it very frustrating but I found it very helpful to go through that kind of assessment process because we had never been assessed. We had never done these kinds of comprehensive assessments before, so I really appreciated the opportunity to be able to think through many of those details of where these guys need support and what level of support they need and what our dreams for the future are and what supports they will need for the future etc. So it was a

really, really helpful snapshot, after a rigorous process, of who they are, what their needs are and what their dreams are. I do see value in that.

The problem I see is that, again, how it's being done province-wide. There are some disparities. There are pay equity disparities, in fact. I can suggest there are disparities in the sense that the vast region that people are serving—again, resources aren't available to back up what people are identifying. So we got everybody's hopes up but we didn't put our money where our mouth is, attached to it. That's part of the problem, and then another bit of that issue is also that we took the same old people who were used to doing the same old things the same old way and put them in a new brand, and it's really difficult to do something new when you have an old mindset.

Ms. Sylvia Jones: Fair enough. Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. DiNovo, you wanted to add to that?

Ms. Cheri DiNovo: Yes. I'd just very quickly thank you for your presentation. I guess I'll segue off of Ms. Jones. You started off by saying that there's no better place to live for somebody with developmental disabilities than Ontario, and then proceeded to talk about how awful it is.

Ms. Rabia Khedr: And I've been taught to be able to do that.

Ms. Cheri DiNovo: I agree with the latter, not the former. I certainly would suggest—we've heard that there are many other jurisdictions that do do things better, and that's good, because we don't have to reinvent the wheel here. We can actually look at best practices in other jurisdictions. We might not take everything from one, but we can certainly take some things from others.

Again, just a thought that there are some—for example, we've heard some good things about Saskatchewan, Australia, the UK etc. But I really thank you for your presentation. You develop themes that are certainly consistent with other presenters, so I thank you for that.

Ms. Rabia Khedr: Thank you. When I say that Ontario is the best, there are worse places in the world. I'm not necessarily—

Ms. Cheri DiNovo: There certainly are worse.

Ms. Rabia Khedr: If I grew up where I was born, I wouldn't be sitting here talking, let alone talking to you.

Ms. Cheri DiNovo: I hear you.

The Chair (Mrs. Laura Albanese): One second. We also have Ms. Hunter. One last question.

Ms. Mitzie Hunter: Thank you so much for your presentation. I believe you did bring a unique perspective to our hearings today.

When you talk about how the system itself needs to ensure that it is culturally and spiritually responsive in terms of anti-racist and anti-oppressive processes, can you expand on that in terms of what you might have seen or what others might have seen?

Ms. Rabia Khedr: We have new and emerging populations, and I've said this to the sector time and time again. The average Canadian experience has been built

on the fact that when your child turns 18, the dominant social value is that they move out, or there's an expectation that they will, and you dread it that they remain behind for years.

That value doesn't necessarily ring true for people coming from other lands and cultures and calling Canada their home today. For example, in many eastern and southern traditions, from Muslim countries, from south Asian cultures, regardless of the faith, it's womb-to-tomb unless you get married and move out. Particularly for a child with a disability, mom and dad will take care of that child until death do them part, or extended family members are expected to. That's just a given.

They're not looking for residential services. They don't want to be put on wait-lists. They want alternative residential models. The only time we seek residential services is in crisis, in absolute crisis, when there have been no other services. As the teacher mentioned earlier, for people with developmental disabilities, their skills and abilities stagnate after leaving school, and eventually, from what I hear in the sector, 50% to 70% of young adults into their thirties develop mental health issues because of that social isolation.

The Chair (Mrs. Laura Albanese): Thank you so much, once again.

Ms. Rabia Khedr: Thank you.

MS. ANGELA BACH

The Chair (Mrs. Laura Albanese): Now we'll hear from Angela Bach, who kindly gave up some of her own time so that the committee could ask questions.

Ms. Angela Bach: That's okay. Good afternoon, everyone.

The Chair (Mrs. Laura Albanese): Good afternoon.

Ms. Angela Bach: My name is Angela Bach, and I actually grew up in the Dufferin-Caledon area, just south of Caledon East, but I consider Toronto my home now.

Those of you who are in Toronto probably last week received a little box of turnovers from me at your constituency office, with a little note attached highlighting the high rate of turnover for people who work in this field, as I work in this field as well. In addition to high rates of turnover, the burnout rate is also quite high as well. And sorry, Cheri; I got to your office after they closed, so I kind of stuffed them in your mailbox.

Ms. Cheri DiNovo: I'm sure they enjoyed them.

Ms. Angela Bach: If the raccoons didn't get them first.

I'm here today because I enjoy my job. I want to enjoy it even more, and I want to encourage more people to come and join me in working in this field. I work front line as a developmental service worker in a residential program. I never introduce myself the way that I just did, because developmental services are not well known or well understood. If you say that you work in developmental services, most people don't know what that means. I usually have to describe it a bit more. I say I work in a group home with adults with developmental

disabilities, some of whom also have physical disabilities or mental health issues.

1410

Once people understand what I do for a living, they're rarely excited about it. I tend to get one of two reactions. It's either a look of aversion like, "Oh, that must be hard work; yeah, I could never do that"; or I get a look of sympathy, like, "Ah, it takes a special person to do the kind of work you do. You must be so kind-hearted." Well, thank you. Yes, having a kind heart goes a long way in this field, but I don't do this work out of the kindness of my heart.

I'm not a volunteer. The reality is that I've chosen this as a career. This is my profession. No one would ever say to a psychologist, "Oh, you must be a very kind-hearted person to do that kind of work," because they are respected as professionals. People with developmental disabilities shouldn't be marginalized, but neither should the people who choose to work with them.

How do we entice more people to enter this field of work? If a student chooses to enrol in a developmental service worker program at a community college and get their diploma, they'll have no problem finding a job upon graduation. This is what students want, right? With so many unemployed recent graduates out there, students want to choose a field of study where there will be job opportunities upon graduation.

So why is the enrolment in these programs decreasing? Why do half of the community colleges in Ontario not even offer this program at all? Because graduates don't just want to have a job; graduates want to have a good job. What makes a good job? I don't mind if you talk. What makes a good job?

Miss Monique Taylor: A decent wage.

Ms. Angela Bach: Yes. So what do you do for a living? "Oh, actually, I'm a member of provincial Parliament." Really—wow. That's a good job, a decent wage, benefits, pension, job security—

Ms. Mitzie Hunter: No pension.

The Chair (Mrs. Laura Albanese): No pension.

Miss Monique Taylor: No, no pension.

Mr. Bas Balkissoon: We'll recruit you to help us.

Laughter.

Ms. Angela Bach: If we look at people who have good jobs—my partner works in construction. He's an iron worker. He talks about the work that he does and things that he builds and the places he travels to. People are actually excited that he's worked in a power plant or built a bridge. I'm like, "Really? You know, I think my work is valuable, too." But he's got a good pension, and not all of us do.

Those are the kinds of things that make a job a good job. Firefighters, police officers—those are good jobs. Those are good jobs and they're also dangerous jobs. They're well paid because there's a risk involved. Developmental services is also a risky field of work to be in, with little protections in place.

I've been to your constituency offices, and I've had to buzz to enter or the doors were locked; Ms. Hunter,

there's a bit of Plexiglas in there. That's all great; I'm all in favour of people being safe in their workplace.

In many fields, if someone becomes violent, they're barred from the program. All of these precautions are good, but they don't lend themselves to this specific kind of work.

The people that I care for often lack impulse control, due to no fault of their own, and they also may be unable to express themselves verbally, so they express themselves physically instead.

Last October, a co-worker of mine received a minor concussion after being hit in the head from behind. She's still experiencing chronic headaches and is in the process of trying to return to her full duties.

You might think that people with developmental disabilities are slow, but I can assure you that they are pretty quick and pretty strong, too.

My co-worker is fortunate that she is a full-time employee and therefore has some benefits coverage. Our employer also provides WSIB coverage. But several employers in developmental services don't provide WSIB coverage.

With the limited funding that's available to developmental service agencies, employers are often forced to choose between providing good care for their clients or providing good care for their employees. They're forced to either cut back on services for their clients or cut back on services for their staff. It's not fair to make them choose. They should be able to provide for both.

Another colleague of mine was recently hit in the face by someone in his care, and his glasses were broken in the process. He's a part-time employee, as many of my colleagues are, and therefore, he doesn't receive benefits coverage. So he's stuck with the bill for replacing the eyeglasses that were damaged while he was performing his job duties. That doesn't seem fair.

The most common injuries that we encounter at my workplace are temporary muscular issues, from either lifting and bending or from being manipulated by a grab, a pull, a twist, a bite, or having your hair pulled and jarring your neck a bit. Your doctor may prescribe some prescription-strength painkillers or muscle relaxants until you heal. The majority of the people I work with are hired as part-time employees or on a relief basis and therefore have no benefits. So if their doctor gives them a prescription, it's my co-workers with the lowest wages who have to pay out of pocket for the damages that were done while they were at work.

We use temporary agencies where I work, like many developmental service agencies, to provide coverage when needed. The employees who come from temporary agencies are generally very kind-hearted people, but they lack education in the field, and they often require a lot of on-the-job training.

Families who receive Passport funding are also put in the position of trying to maximize their funding dollars by hiring contract care providers who may not have the qualifications to provide the best care for their loved ones. This individualized type of funding is a quick fix

for desperate families. What families need are good public services. There are too many instances where families are so desperate to find care for their child that they resort to drastic means. I'm sure you've seen the articles in the newspapers:

Emilia Arthurs, in Sarnia, was dropped off at a respite home in September 2012. Her parents surrendered her at that point and didn't return to pick her up. That's desperation.

Phillip Telford, in Ottawa, was dropped off at a government office last spring. His family had been receiving Passport funding, but it's not enough.

Qyzra Walji was a happy teenager living in London with her parents. In addition to the demands of caring for Qyzra, her parents were facing deportation, and she passed away with her parents in an apparent murder-suicide. This is why I do the work I do, because I can't handle hearing another story of families so desperate and resorting to such drastic measures.

1420

In 2007, Keith Croteau was a very small man with a developmental disability and he was living in a nursing home, as many are placed in nursing homes when there's just nowhere else to go. Keith passed away due to injuries following an attack by his roommate in the nursing home because Keith was hard-of-hearing and needed the TV loud. He usually had headphones, but they were broken. His roommate didn't like the noise of the TV, and Keith is no longer with us.

On one occasion at the group home where I work, one of the residents obtained a knife from the kitchen when it wasn't locked, and threatened another resident with it. Now we had the staffing ratio in place, and my skilled co-workers were able to separate the two and to de-escalate the situation until police arrived. Those two no longer live together, but both are still healthy and live well in their separate homes. So there's an example of the difference between adequate care and inadequate care.

I'm going to be mindful of my time and skip over a couple of other stories.

It's widely acknowledged that Ontario must create new jobs, so here's an opportunity to create these jobs. I know and trust that the formation of this select committee is going to result in a shrinking wait-list. But once these people on the waiting list have services, who's going to work with these people? Literally, who is going to do these jobs? I already have two jobs, and a lot of my colleagues also are juggling two or three different jobs. Who wants to enter a field of work where most of the jobs are part-time or casual, without benefits, limited vacation time if any vacation time, where they're being exposed to physical and verbal aggression which is known to be an inherent part of the job, where your employer may not be able to provide WSIB coverage and where the wages are so-so? The most rewarding part of the job comes from within, when I think, where would these people that I work with be without the services that people like me provide? Would they be like Emilia or Phillip? Would they be like Qyzra or Keith?

Taking care of the community's most vulnerable people must be a part of the larger plan to improve the economy. Until developmental services is a respected field with decent wages, it's not likely to be a career of choice attracting new workers. In my job as a developmental service worker, sometimes I feel like I wear the hat of a nurse, a counsellor, a teacher, a family therapist, a recreational coach and a behavioural interventionist. It's a complex job requiring multi-tasking, patience and a high level of responsibility. Workers in comparable fields have decent wages and pensions, and we don't receive a pension and we often live paycheque to paycheque.

About two years ago, the agency that I work for was faced with the serious possibility of closing its doors—eight group homes and a large day program, over 100 employees, and they were looking at closing. In spite of the growing wait-list and so many families desperate for services, the lack of funding meant that they really had to consider keeping the services that they currently offered. Is this the future of developmental services in Ontario?

Thank you for the opportunity to share my story and some of my concerns.

The Chair (Mrs. Laura Albanese): Well, thank you. It's too bad that we can't ask you any questions.

Ms. Angela Bach: That's okay. I was a little bit nervous for the questions and stuff, too. That's all right. The person before me spoke very well, and I was glad to let her have the question time.

The Chair (Mrs. Laura Albanese): She did, but so did you, and you can really tell that you do what you do with a heart. You've described in a very adequate manner what adequate care is and how it can be provided by passionate people, but they need to be paid well.

Ms. Angela Bach: Thank you, everyone.

The Chair (Mrs. Laura Albanese): Thank you, Angela.

INCLUSION INITIATIVES CORP.

The Chair (Mrs. Laura Albanese): We'll now call on Inclusion Initiatives Corp. Good afternoon.

Mr. Don Hill: My name is Don Hill. I am the executive director of a fledgling charity called Inclusion Initiatives Corp. Our mandate is to create job opportunities and programming for developmentally and intellectually disabled individuals. I'm here today to add a voice, or perhaps an additional voice, for the idea of social enterprise and what it can bring to this issue that we're here discussing today.

I don't think anyone would argue with the point that we have a significant problem before us, that typically there's probably not enough money to satisfy all the demands that are being put on the system. I would like to advocate for growing that pie and finding ways to look at this problem in a new light.

For instance, we are starting two initiatives as a social enterprise. We are a charity, so any money that is derived from what we do goes back into programming for the people we serve, along with wages. We are in the midst

of opening a recycling effort, and we are starting a gourmet cookie effort. Our job is to bring innovative business practices and marketing to the table in these efforts and find ways to satisfy needs in society that we know currently exist and that we're capable of delivering on and using this money to solve this problem, or to help solve this problem.

There were a couple of points that were made that I just wanted to comment on. The DSOs so far have taken a lot of flak from the way that things have worked out so far, and you were asking if you thought there was a place for the DSO and what role that might be. Clearly it would seem that the DSO is just a service delivery mechanism. I think it could be a lot more than that.

Many of these individuals, once they leave the public school system—developmentally disabled, for instance—at the age of 21 really have very little as far as a place to go, somewhere to attach themselves. The DSOs may find it very easy to develop a new perspective on creating entrepreneurial efforts like the one that we are in the midst of creating, sponsoring these efforts, and standing up and being a focal point for people who are trying to solve this problem.

For instance, I would ask you to recall—what was it? Once upon a time, we had a Bill 30 that created a school system where no school system existed. The government stood up and created a bill, and assets were diverted from the existing system. All of a sudden, we had an additional school system.

Currently in the Education Act we have regulation 444. Regulation 444 says—this is me giving you my short rendition of it—that the school board can dispose of properties, but it has to go to certain organizations first to see if they have a need for them. This community could sorely use those assets but has no one to stand up for them, and they are not included in that argument or in that equation.

1430

If we could take public schools that were closing and use them as economic centres—just perhaps to put out a thought—where we could have classrooms turn into small businesses, have social areas, have service areas where we can run community-based organizations for people in a community with assets that we've already invested in, that are already there—and to run these businesses, all we have to start doing is, the government needs to have a new policy that if you want a government contract, perhaps one of your scorecard points that determines whether you get it or not will be: Do you do business with social enterprises?

For instance, it's not a big deal for us to collect cardboard from an organization like Walmart. They've got it in a place. We need a truck; we need a driver that can drive that truck. But to bring that back to a centralized depot and process that cardboard is something that a lot of these individuals could be involved with in a meaningful way and give them participation. You're probably aware of the Aspiring Workforce document that was recently put out, where they talk about the import-

ance of a job, and I think that is very true for all people. People need to have dignity, and work helps provide that.

Just in case there are any questions, I'll try to cut this short, but I would encourage you to think about social enterprise. Social enterprise is a very broad subject. There are a lot of different structures within that, but I can suggest to you that social enterprise done under the auspices of a charitable designation where there is accountability to the government in following what your objectives are, once they've been stated and approved, is a fairly safe way of bringing in new people to provide services not just to this community but to the community at large, and finding ways to bring in new revenues that will be used to satisfy the needs of these individuals, instead of continually coming back to the government well that often has difficulty meeting all the needs. That's it.

The Chair (Mrs. Laura Albanese): Wow. That's very interesting. We do have time for some questions. It is Cheri's turn. Ms. DiNovo.

Ms. Cheri DiNovo: Yes, thank you very much for coming before us and speaking to us—very interesting. We have heard from a number of presenters, actually, about social enterprises, and I think we probably are all in agreement: They're wonderful initiatives. We've heard of laundries, restaurants, cookies and other things—everyone needs to have a job that they feel some sense of pride in; everybody needs some place to go, I think the presenters today said, 9 to 5. That's so important, so I thank you for highlighting that.

And your other suggestions, you should know that you're not alone. They represent themes that we've heard, so thank you for adding and augmenting those.

Mr. Don Hill: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I'm particularly interested in your organization working closely with the school board and local community with respect to your social enterprises, because regulation 444 allows organizations like yours to work with local council to then pick up, through reg 444—to build a system. I'm not sure you're aware of that.

Mr. Don Hill: Well, to be honest with you, I'm pleased to hear that. I don't consider myself an expert on that. I'll have to go home and research that. We would love to pursue that sort of activity.

Ms. Soo Wong: So working with the local school board, that's one suggestion, working with the local school trustee—

Mr. Don Hill: Yes.

Ms. Soo Wong: —and most importantly, with one of those 10 groups that you just mentioned, under reg 444, and they will then leverage your ability to pick up that empty school. It has been done here in Toronto. I've seen it done in Toronto. I'm going to encourage you because I think it's a really innovative opportunity and provides employment opportunities for this particular sector. So keep up the good work. I think there are lots of good things coming out.

Mr. Don Hill: Thank you.

Ms. Mitzie Hunter: I also want to add to that. We have recently announced our youth employment fund. A portion of that is for social enterprises and social entrepreneurship. The Ministry of Economic Development and Trade also has initiatives targeted at social enterprises, and there are assistants out there to help scale the projects and support people in getting their own projects going, so I would definitely encourage you along this path. It's not only job creation, but it's job creation that has a good social outcome, and you're adding the additional lens of people with developmental disabilities, so I think that's excellent.

Mr. Don Hill: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Elliott?

Mrs. Christine Elliott: Thank you very much, Mr. Hill, for coming before the committee today. The concept of social enterprise is something that we have heard a little bit about. I'm wondering if you could tell us, in your particular case, how it works, how you got your organization up and running, and—I guess the recycling business is the one that you've got launched already—

Mr. Don Hill: That's right.

Mrs. Christine Elliott: —how that operates.

Mr. Don Hill: In essence, it's very simple. We have a couple of individuals, we have a van, and we'll go out and look for—our initial foray is into metals and then we would like to get into paper fibre. But with metals, we're currently negotiating some deals with people like Direct Energy and other people who are replacing furnaces, water heaters and refrigerators, where we can take these large amounts of metal—where we're not hunting for this metal but we've got a pre-organized location we're picking up from. Then we can take it, disassemble it and get it into its highest form, and we just sell that on the open market.

We hire people with disabilities to do that. Our mandate from the government is that we're allowed to hire anyone with a disability, but our heart is with developmental and intellectual disabilities, so we want to make as many opportunities in that area as we can. Not all of these people are capable of driving a truck, whereas someone with lupus might be able to drive a truck. So we can meet our obligation to the CRA and we can create opportunities for these individuals who may be able to use a screwdriver or a drill and take screws out of a furnace to strip it down, with proper supervision.

That's what we do. How we started: I started this to help my daughter, who does not have a developmental disability. She does have a disability, but her goal in life is to work with people with developmental disabilities. That's what she would like to do. Unfortunately, she had to drop out of university because of her disability this past fall, but if we can create this opportunity to serve people, there will always be a place for her to participate. That was the driving force, along with a niece who has Down syndrome.

I just think that, with good business practices—Gateway did their laundry centre, and they've done a

phenomenal job. It just shows you what people are capable of. The market was there for the product, and they went out and got the contracts from the people they were working alongside. Now they've created tremendous opportunities for people who otherwise wouldn't have had them.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Thank you very much for appearing before the committee and for advocating in favour of social enterprises.

Mr. Don Hill: Thank you very much for the opportunity.

1440

MS. CHRISTINA BUCZEK

The Chair (Mrs. Laura Albanese): Next we will hear from Christina Buczek. Good afternoon.

Ms. Christina Buczek: Hello. I've asked that an article be passed around. This is an article from Prime Minister David Cameron, who is the father of a severely disabled child, and what he shares, with his own experiences, is what he sees as the five main lessons he learned that he would like to see implemented, as a father. I just wanted to share that with you.

I think that probably from what I've seen of the testimonies that you've heard, you've pretty much heard the gamut. It seems to me that you've got many, many people who've said a great deal. So I don't really feel I could probably do as much justice or say it as eloquently as many of them have. But I do have a few points that I think are important from my perspective.

One of them is directly related to the article, which is the issue of direct funding. I think that direct funding just makes the most sense of anything, especially when we look at the fact that funding has not been increased, and the number of families is increasing monthly. If we want to really make the best of it, direct funding is the easiest way to minimize the administration, the bureaucracy and the processes that are involved, which I think if you spoke to most families, they would tell you that the processes that we are put through are humiliating and demeaning. They require us to be totally without privacy. We have to give a lot of personal information, we have to talk about the most difficult aspects about our children, and we're made to feel like we're begging. It is not something people would want to have to go through. I think you'll see in the article, it says pretty much the same thing.

Direct funding also stops treating us like we're incompetent people who don't know how to spend money wisely. It seems like we're nickel-and-dimed to death because there seems to be this fear that we're somehow frauds who are going to spend it on drugs and booze or something. You really get to feeling like you're constantly having to defend yourself. You have to prove everything. There is no sense that there's any trust or thinking that you're doing the right thing.

I've also seen programs that have started out well-intentioned, but when they fold out, what's really

interesting, is that they start reverting to the same old practices. What was supposed to be a direct funding option for parents quickly became one where the parent, in fact, could not submit their own plan. They had to sit down with somebody, arrange an appointment, sit down with a social worker, and that person had to write it all down and had to basically justify and verify whether or not they even agreed with the parent that this was an appropriate plan. Without their seal of approval, the parent couldn't have the plan. This is supposedly a family-directed plan. Then, the plan said, "Well, you know, we've come to realize that some parents don't have transportation and their child can't go on a bus, so we're willing to say it's not unreasonable to pay for a taxi so that the caregiver and the respite provider and the child could be taken to a program." Well, that was one of the fundamental positives about this program: finally recognizing that these are some of the basic hurdles people have—and they took it away. They said, "No, you can't use that for a taxi." So a lot of families are basically out of luck. I really do find that that's problematic.

Now one of the parents I know said, "You know, the problem we have is too much system and not enough service." That's very obvious. I hate to say it, but the road to hell is paved with good intentions. I'm sure everyone here has really good intentions, but, believe me, you're doomed to failure unless you do two things. Fundamentally, you're doomed to failure if the families that you're supposed to serve are not involved at every step. This is because you may think you are doing something that looks really great on paper, everyone in your meeting agrees that this is great, but nobody has thought to bring a couple of parents in to say, "That won't work," and explain to you what might be a simple reason why it won't work. But if you don't do it that way, and you think it's going to roll out just the way you've planned, it's not going to work. Anybody who invents something—it's like inventing a machine and expecting it to work perfectly the first time. It's not going to work. You're going to have to tool with the machine; you're going to need to understand what our lives are like and what hurdles we have that are preventing us from accessing the things that we need. To me, that's where—we really need to say that parents have to be involved.

The other reason I'd say it's doomed to failure is if you're working at the planning stage of it and the nuts and bolts to make it actually function and work are returned to the public service bureaucracy that you have. It's that very system that keeps being duplicated over and over that is the very thing that is problematic. We've got silos of different ministries. Parents can't move funds from one silo to another. Even though their child is supposed to get certain services in one location, they can't move it to another location.

My daughter was actually developmentally delayed, severely autistic, non-verbal. She requires two one-on-one assistants. She's under what's called a SIP grant. You're talking the most high-risk, most vulnerable, most developmentally delayed of anyone in the system.

She attends a school here in Toronto. I bet most of you never even heard of it and I'm sure none of you have ever been there. I can tell you, because whenever we've invited anyone to come to that school, not one has shown up—not one.

The school is fantastic. It's called Lucy McCormick. It's with the Toronto school board and I—

Ms. Cheri DiNovo: I've been there many times.

Ms. Christina Buczek: Well, probably because it's in your vicinity. But in all honesty, we've invited Ministers of Education to come and they have not come. The reason I say that I believe everyone who is on this committee needs to go to Lucy McCormick is because if you don't go there, you don't know your client; if you don't go there, you don't know what they're really all about.

We had a meeting last week there. Parents talked about how they don't really have a command of English, they don't use computers, they don't know about this meeting. A lot of people had never heard about this meeting happening.

The children who attend there: It could be a six-foot guy, 250 pounds, physical, the mentality of maybe a two-year-old. But you've got people dedicated to working with them who know what they're doing. That's few and far between, because when we have people graduate from teaching college, they have the minimum training in special ed; they were required to take one general course in special ed. Our children are the guinea pigs of people coming in with no training and they're learning on my child, who doesn't have a voice, who cannot speak, who barely communicates. That's not fair to my child.

Every year, my child, if she gets a new teacher—it's like starting at square one for them to have to learn her language, her way of communicating, and it can result in all kinds of complications. So to me, a fundamental problem we've got is an education system for teachers that says, "You go for one year. In that one year, you'll get maybe two placements out in the community, and then the next year, you're a teacher." We need some form of a mentoring program within the system that takes the teachers who really know what they're doing, with the staff who know what they're doing, and they have to learn. I shouldn't have a person assigned to my child who has never worked with autistic people before, doing things that are fundamentally wrong with her. Okay? They really have no idea what they're doing. I am trusting my child, who cannot tell me, "Mom, I've had a rotten day. This is what happened me," or "That's what happened to me"—I have to rely 100% on how she comes home.

I'm even lucky I got here today, because my daughter is a teenager and she's decided there are some days she doesn't want to go to school. She's physical. She has nearly thrown me down the stairs. My husband and I together cannot physically get her out the door unless my son happens to be home and can help us get her to the vehicle, where she is then strapped in in a harness to get her to school. I'm reaching the point where I physically cannot deal with it.

So yes, there's a crisis here, and I think if you go to that school and you really get to know your client, then maybe you'll get a real picture of what you're dealing with. It's almost like having a bunch of doctors sitting in a room talking about patients and their family life, never having gone in and visited that particular family. To me, it's fundamental. You really do need to go in there and meet these people.

1450

I even talked to other parents of autistic children. It's funny; we're talking at cross-purposes. They tell me to just tell my daughter to do this or that. When I tell my daughter's assistant this, they crack up laughing, because my daughter cannot be reasoned with in this way. There's a huge difference between talking to a two-year-old, who you cannot reason with, who doesn't hear what you're saying, who doesn't get it, versus talking to a child who can actually speak and be reasoned with. It's night and day. To me, that's fundamental.

The other thing I was going to mention is, the system really is set up with inertia—it's there to preserve itself. No employee is going to find a way to save money by getting rid of their own job. No unit is going to say, "I know how we can save money; I can get rid of three of my staff." The system just keeps perpetuating itself.

I hate to use it as an example, but there were a lot of people who saw real value in creating an IBI program, and I can tell you, the way in which it is actually maintained and how it functions is so ineffective. It is lining a lot of people's pockets, for their careers and their jobs. The amount that actually gets to our children—I hate to think what a small percentage it really is. Those people are not going to tell you that they're not needed. No one is going to say to you, "You can cut me by half; you can easily cut me out." That's how they make their income. They're not going to tell you that.

I even had people say to me, when I was showing concern about something they were doing that was, in my view, detracting from my child's services because of how they were spending money, "What do you care? It's not your money." I actually had someone say that to me.

I'll tell you, when it's my money and I go out looking for services, I get the respect I need and I get to set what I need them to do for me. It's very different. Putting the money in the hands of the parents directly cuts out a lot of the bureaucracy; it stops creating all the hurdles that we're expected to jump over—and it will actually put money where it's needed.

A lot of families with special needs—you've probably heard that between 50% and 80% are divorced. You've got single-income families, so the need for respite is very high. You also have a lot of families where one person is staying at home; one is a non-working spouse.

When we see that the community is aging and we've got people who are having dementia, Alzheimer's etc., a lot of families are now going to end up having to have a person at home being a full-time caregiver. If we look at that same person and put them in a facility, that's 24/7 care.

Amanda Telford was right when she said that 24/7 means three full-time jobs, seven days a week. Do we ever look at that and say, "What does it actually cost us, as taxpayers, to provide some of the services that we're doing out there right now"? Only when you get a real handle on what those expenses are—and those are strictly concrete expenses.

Why is it that funding for parents who are doing the job at home and trying to keep the family member at home—why are they going through so much difficulty for every penny they get? Why is it not increasing?

The cost of me getting a respite service has really increased. I've only ever been able to get people who are professionally trained. I often need two people—or I need to ensure that my son is there—because of my daughter's physical behaviours. That costs a lot of money, but I've not had any increase in any funding. In fact, I've taken an 80% decrease—because I have two special-needs children. One of them turned 18, and I thought it might be cut in half. I lost 80%—80%. So I don't know what's going on with funding. I just got another letter in the mail saying, "Based on your income—\$60 less a month." That was it; no explanation. My income didn't go up, but I suddenly have \$60 less a month. I need every dollar—80% gone.

What I really think makes a great deal of sense is, instead of constantly looking for more dollars to make available—we have so many families living at poverty level who are paying income tax. They're at poverty level, but they're paying taxes. Why are we not creating a process where it's put right on our taxes? Then I don't need to create a big administrative system; people just need to claim on their income tax, which already has paperwork indicating from a doctor that, yes, there is a severely developmentally delayed child in this home, and give us the bigger tax break so that parents will be able to retain more of their own income to use for this purpose. It makes just too much sense to me to do it this way that it obviously defies the logic of government.

I also believe in income-splitting, since so many of us have a stay-at-home spouse. Income-splitting would make a huge difference. We are taxed right now—I actually would be better off divorced than I am now as a married woman with respect to how my income tax is affected by my child. As I said, I have two developmentally delayed children—two children, that is, with disabilities. Something is wrong when the government is saying to me, basically, "You would pay less if you divorced your husband." That doesn't make sense. Income-splitting makes sense because we, as a society, keep espousing values, such as wanting the family to be able to stay together.

We know that the most important thing about a caregiver is that they actually have a love of the person they're caring for. Pediatrician Penelope Leach said that the most significant factor in any caregiver relationship is that the caregiver must fundamentally love the person they care for. Instead, we're putting them in various forms of institutions because families can't cope at home. If we really believe that we should create a society where

people are able to care for them at home to the best of their ability, or to make it work, then let's create an income tax system that reflects that.

Let's say that the spouse who stays at home is taking care of either a disabled adult or disabled children—that they get some form of a tax break to enable them to continue to do this. I know myself, I would prefer to keep my child at home, my adult child. I don't like the idea that I have to go and drop her off at some facility and say, "I'm not coming back," as a way of getting her in the system. But the system is now being run on a crisis basis.

There are a lot of services once the child becomes 18. We've already been told that for a lot of the services, there are huge wait-lists and we may never access them. We say, "Be careful. It's not a wait-list." It's not a wait-list; it's a priority list, which means that whoever is considered a priority—in other words, who is in the most crisis—is going to get the service, which means that pits us parents against each other in going forward and trying to explain why my case as a crisis is more significant than someone else's. Can you imagine that? We're in crisis if we have to give up our kid, period.

The last thing I'd say is, any of us being told, or learning in the newspaper that a parent has killed their child and then committed suicide—it's not a shock to me, and that's scary to know, because I know that people have reached the end of their ropes. There are no services. I have seen it happen where they are told, "There is nothing we can do for you," and the parent is supposed to go home. They might get some counselling as an option for the parent, but no services for the child, because there aren't any to be given.

That's all I have to say. If you have any questions, I would be happy to take any questions.

The Chair (Mrs. Laura Albanese): Thank you. We really don't have much time for questions—if anyone wants to make a closing comment. Otherwise, I shall—Miss Taylor.

Miss Monique Taylor: I just want to say that I'm sorry for everything that you're going through and that your family is going through. It's absolutely horrific. Nobody should have to feel the way that you feel.

Thank you for coming here and being brave enough and taking the time out of your very busy life to come and share that with us today.

Ms. Christina Buczek: I really had not wanted to be so upset when I came. I knew that, unfortunately, I'd get emotional about it regardless.

I do honestly want people here to please, please go to Lucy McCormick Senior Public School to see what is ideal. Lucy McCormick is the only school that has all developmentally delayed students. It is the only school that has developmentally delayed with other multiple-needs children. It's the only one in the board. There are others that have both MID and DD students—mild intellectual delay and developmentally delayed students.

1500

The reason it's such a great school is that the people who are there are phenomenal. If my child could stay in

the same school for the next 10 years, I'd be thrilled. But she can only stay there till she's 21. When I look at everything that's done at the school, every parent there would say, if this could be duplicated, this would be phenomenal. To me it's really worthwhile looking at because all the students are DD.

What I've discovered is that the staff look at everyone as having the opportunity to do something there; whereas at other schools, I found there was a real tendency not to include the DD students. In this instance, you'll see they're all included. Despite all the ups and downs that we've gone through, we now have my daughter in what I'd consider the best solution for her at this point in time.

The only small comment I'd make is that what's interesting is that the Ontario government has introduced a lot of mentorship programs and apprenticeship programming for regular students, and they do have some for MID students even. But there are none—nothing—for DD students with respect to actually using whatever they can learn at the school and having it apply so they can go out and actually work somewhere, even as a temporary thing to do with their school. It doesn't exist. The Ontario government has created a document called Education for All, and it was based on the concept of equity, so the idea is equity for all. But in this particular aspect of creating a way of bridging between going to school and then getting a job, the DD group is the only group that has nothing.

The Chair (Mrs. Laura Albanese): Thank you for coming here today. On behalf of us, we really do feel your frustration, but you've illustrated everything very clearly.

Ms. Christina Buczek: You're welcome.

The Chair (Mrs. Laura Albanese): We won't forget it. Thank you.

Ms. Mitzie Hunter: Madam Chair.

The Chair (Mrs. Laura Albanese): Yes?

Ms. Mitzie Hunter: With the last comment about the mentorship and co-op programs, can we get from the ministry what is available for students with developmental disabilities by way of those types of supports?

Mr. Bas Balkissoon: Maybe we should ask about the Ministry of Education's guidelines for providing—

Ms. Mitzie Hunter: What is the Ministry of Education's guideline on providing students with developmental disabilities with options for mentorship and co-op?

The Chair (Mrs. Laura Albanese): Thank you.

MS. CINDY MITCHELL

The Chair (Mrs. Laura Albanese): We're going to call now Cindy Mitchell to come forward. Good afternoon.

Ms. Cindy Mitchell: Good afternoon. Hello, everybody. We meet again. Today I come before you, though, as a mom. Last week I came as a mom, too, but I went to Ottawa with my daughter, and I was representing Family Alliance Ontario.

Karen was supposed to be here today, too, but when I talked to her this morning about it again, she made the decision that this wasn't the best place for her to be, so she declined coming here. She would sooner do what most people would do; she would prefer to participate in valued, meaningful kinds of activities within our community. That's exactly what she's doing today.

Karen felt it was much more important for her to go to her job, to go to her volunteer role, at a local community school. It's actually right in my neighbourhood in Whitby. She went there instead.

It's a very valued role for Karen. Actually, a year ago, she was nominated for an Ontario Volunteer Service Award by that school. She's been there for seven years now in the capacity of a volunteer. The principal from that school moved a year ago and gave my family a call and said, "You know what? Karen is such a great volunteer. She could teach people at this brand new school, called Chris Hadfield school, what it means to volunteer." So she now works there one day a week, too. Karen takes her volunteer roles and her work roles very, very seriously, and she's absolutely one of the best volunteers and workers this school has. That's clear because of that award. You've heard that about people with developmental disabilities from many, many presenters besides myself.

Karen is aware that I'm speaking about her today. She has given me permission to do that. She knows that I'm speaking about the experiences of my family, and the impact that systems in Ontario have had on our families.

I thank you for this opportunity—it's always hard to talk about your own family—on behalf of my family and my very wonderful daughter, Karen Inwood, to be here. I'm really pleased to speak to you today, in part because this committee is very inclusive. It encompasses all political parties, and all of you have chosen to sit here.

I think this is well worth the cost to me—my effort, my time and the emotional cost of sharing my family's story, because I think there is a greater potential that your recommendations could actually go somewhere, and possibly even be helpful to other families, and especially to our vulnerable sector of people with developmental disabilities.

I think this is so because you are working together. All parties are working together. I believe that you feel that the current system is not working, and I believe that what you have heard thus far supports this statement entirely.

I believe that the root problem is that the system is built, and continues to be built, to support the system. You just heard from this wonderful, eloquent mother about that. It's built to support the system, not the person, and especially not their family.

This problem crosses all systems, so I'm going to start with my story and our interaction with the first system, and that was the educational system. Karen started school in a small northern community: Hermon, Ontario. The public school was the very public school that I went to as a child.

The school board in that area had a special education class in Bancroft, Ontario. That was a one-hour bus ride

away from the Hermon school. They informed me when Karen started school that she and two other kids at the school were going to be bused together—one hour away, one hour back—to this special education class.

The two other families and I, who happened to know each other, got together, and we tried to challenge the logic of this idea and the cost of this. Ultimately, all three of us pushed back, and our children remained in our local school. We pushed back against the system because we believed that our children were better off and safer in their neighbourhood schools.

We three parents then pushed our local Community Living association to do what it stated its job was. We said, "You need to stand up for us. You need to take a position with our families, and you need to support our children's inclusion in our local schools." This was my first experience of the power of a small group of families—in this case, just three of us—coming together to effect change at a local level in our communities.

If Karen was here right now, I know what she would tell you. She would tell you that she remembers riding on the bus. She remembers attending that school in Hermon. She would say she was very happy and was not afraid, because her big brother Kyle and her friends also took that same bus. Coincidentally, the bus driver who drove Karen and Kyle also drove me and my husband, at the time, as a child. This is what keeps my daughter happy and safe: people who know her, real, authentic relationships—not paid relationships—and real community inclusion.

I moved to Whitby when Karen was seven years old. We lived three blocks from E.A. Fairman Public School in Whitby. At our first meeting with the school, to introduce them to our beautiful daughter, they suggested that she be bused to a segregated school at the other end of Whitby, away from her new friends on the street, away from me as a mother and away from her brother who she adored.

We challenged that recommendation. We challenged that process, and that process—for me, as a young mother—took us right to a regional IPRC committee. It shouldn't have done that. It was emotionally draining. This challenge was not as easy as I had thought, because one teacher at that meeting suggested that I was a very abusive parent. She suggested that I was abusive because I was putting Karen in a situation of possible future bullying by others.

Thank goodness that, at that time, I was then connected to an organization called Family Supports Institute, which was a precursor and would eventually become Family Alliance Ontario, which I spoke to you in Ottawa about. Again, the power of families coming together with other families, supporting each other, standing beside each other, helping each other withstand the pressure of systems, helped me to not allow my daughter—my beautiful, wonderful, self-confident daughter—to be segregated, to be marginalized, to be devalued, to be sent to the back of the bus or the other end of the community.

1510

I'd like to point out that actually I have a wonderful supporter in the room. She has left—oh, there she is. Dawn Roper. She was actually one of the first moms I met when I moved to Durham—one of the very first moms. She was a catalyst of starting Family Support Institute, which is now Family Alliance Ontario. Dawn will be sending a presentation to this committee. I hope they will take time to read it because I am absolutely confident it will be filled with the history of this system, which you need to understand. You need to understand how we got here so that we don't keep doing the same stupid things over and over again.

Back to my family story: For the next several years, up until high school, Karen walked or rode her bike to a regular class at her neighbourhood school like all the other kids in our Whitby, Ontario, neighbourhood. I fought for that, though. Again, at the start of a major transition, when it should be easy for families, it wasn't. When Karen started high school, again the education system and I bumped heads. They were very unsupportive and didn't have the imagination to imagine how someone like Karen, whom you guys all met the other day, could be included in her regular school.

With zero knowledge of unions and this process in the system, I watched—sorry, I've missed my spot here. In grade 8, Karen had this wonderful EA. This is what relationships are about. She had this wonderful EA and she had a circle of friends in grade 8 because she was alongside the kids in our neighbourhood attending a regular school. With zero knowledge about unions and the process in the system, I asked this wonderful EA if she could move with Karen, and I asked the secondary school system if she could move with Karen. I was advised that she would have to apply for the new position. The EA and our family were advised that this EA would essentially have to leave her position in the elementary system—leave her job—and apply for the new position in the secondary system. Effectively she would risk ending up not having a job, potentially, if she didn't get hired. I'm happy to say that this wonderful, brave EA took that significant risk. She got the job and she supported Karen's inclusion throughout high school.

My point in telling you this story is to help you understand that it's people and relationships that move us toward our goal of social inclusion—the right people, the right relationships. That wonderful EA, Wanda Sharp, still contacts Karen; she's still in Karen's life. The grade 8 friends remained friends throughout high school. This, of course, was supported by a good EA, who understood inclusion. In their graduating year, these friends from grade 8 were instrumental in lobbying the whole school for Karen to be voted prom queen. Karen taught a lesson to all those girls about the value of all people being together.

I wish I could tell you that Karen went from that glorious high school experience of prom queen to her wonderful role as a highly valued elementary school volunteer, but I cannot because that is not the case. The

thing about life is, things happen, life happens, and when it happens, it happens to the whole family. In our case, a few of the major things that happened were marriage breakdown—that happens a lot, you heard earlier, and I can attest to that. The second thing that happened in our family was that I was diagnosed with stage 4 cancer. And then Karen's best friends from high school went off to college and university. Karen had no place to go off to. She went directly to our couch and mom went to a stem cell transplant. This experience was extremely sad for Karen, and she suffered a significant depression during it.

We heard about and we applied for the new CICE program at Durham College, but Karen was not accepted. We would apply two years in a row for that program until Karen said, "Stop." This personal rejection she felt during the interview and the application process was too painful for her to endure a third time in her life.

As a mom, I got very excited—I was even actually somewhat hopeful—when I heard about this new program called the Passport Program. Of course, I gathered up my energy and my bald head and I applied for it. Given that I was ill and there was nothing available in the community, I thought for sure I would be approved. That was in 2006. Just like thousands of other families in Ontario, I'm still waiting for that to happen. However, on a positive note, our SSAH increased in 2005. Certainly, I believe this increase was due largely to the fact that everyone thought I was going to die. The flexibility of SSAH funding was helpful and supportive to my family and to Karen during this crisis in my family, a situation that I am certain would not be the case with the Passport Program and the new rules.

Cancer care and treatment doesn't end in six months. The new rule is six months—you can have some flexibility. Well, I'm standing here today, or I'm sitting here today, before you, so you can see I managed to elude death, and with a clinical trial high-risk treatment, I went into remission and I'm still in remission. In 2007, I was able to come off CPP disability and join a wonderful local organization that actually is in the DS system sector. At the same time, I joined a local family group of parents who wanted something different and imagined a better life for their kids. Through that group—not through my employment in the DS sector or having any knowledge about that sector, but through that group—I was able to access independent facilitation and planning.

Our facilitator, for a short time—because money ran out eventually—was able to help some of us develop plans for our sons and daughters. Access to independent planning and facilitation, along with being with a group of another, of other families—I get tongue-tied. It's really emotional when you have to sit before you and bare your family's soul, but I think it's important. So this access to independent planning and facilitation, along with being connected with a group of other families, really assisted me and, I'm sure, the other families in this group to learn and grow together. Together, we're able to dream; together, we're able to imagine a better life for our sons and daughters. By being witness to each other's

stories and being present in each other's lives, and through our relationships, each of us was able to take concrete steps in better directions for our kids. I believe that families have to be in the company of other families if we here in Ontario are ever going to be at a place where more people with developmental disabilities get to experience authentic social inclusion—not a program, not a service, but being present and valued and contributing in their community, like my daughter Karen is today.

I was supposed to bring with me today a video called *In the Company of Others*. It was actually produced by Durham Family Network, which I'm part of. I wanted to encourage you to view it, so I'm going to have to courier it down. It is a really good little short video, produced by tax dollars, that really will demonstrate to you the importance of families coming together, being in the company of other families, and that through relationships and capacity-building among families, things can change, that we can actually move down a path and move towards real, authentic social inclusion for people with developmental disabilities.

Families coming together with families really doesn't just naturally happen, especially in groups of more than two or three. This intentional networking work is not really happening here in Ontario right now. It's actually quite prevalent in Durham region, but across Ontario it's not something that happens quite naturally. It certainly is not something that is supported by the developmental service system or is even on the radar of the transformation plans and ideas; I can't see it anywhere out there.

This committee has heard from other family groups; I know you have because I read them. They are telling you that is so, too. Some of those family groups—I think Deohaeko presented yesterday and probably told you about how, as a group, through families coming together, they were able to figure out and build good lives for their sons and daughters. This is over 25 years ago, so I can't believe we're still knocking ourselves across the head trying to figure this out. These families, 25 years ago, were figuring this out, and continue to figure it out together. With little money, they have sustained themselves, and their sons and daughters still have good lives in our community.

1520

I remain a single parent. I'm a caregiver. Now, I'm also a caregiver of two elderly parents, who I moved to Whitby two years ago. Five weeks ago, they moved into my sister's home. So I spend many hours supporting my parents to give my sister a break.

Ontario continues to fail caregivers, to recognize our lost earnings, to recognize our lost pension, to recognize the time and effort we contribute. The vast majority of us—the high vast majority of us—do this willingly and lovingly, but we are deeply afraid of the cost of this: the cost to our health, the cost to our future, the cost to our children's future, especially as we age.

Up until a year ago, I was spending in excess of \$7,000 of my income to ensure my daughter had good support while I went to work. Not many women share

their age, but I will: I'm 56 years old. For six years, I was certainly unable to save for my daughter's and my senior years. My income level was not enough to sustain this personal financial contribution, so I was deeply grateful when someone I know suggested I should teach in the DSW program at Centennial College, seven years ago.

At first—

The Chair (Mrs. Laura Albanese): Ms. Mitchell, I just want you to know you have about a minute left.

Ms. Cindy Mitchell: Okay; I'm nearly done. At first, this additional role on top of my already full-time job helped me to save for old age, so this past year, I've been able to save. But I still continue to work there because old age is coming faster than I can save. I jokingly tell this to parents, "I'm going to work till I'm 70." But it really isn't a joking matter; it's my life, and it's my daughter's and my family's life.

I know it is similar to the life experiences of many Ontario families. In telling my story and giving you a short glimpse into my life and my daughter's life, I hope you will think about what you will eventually recommend to Ontario and think about some of the things I would suggest. First—

The Chair (Mrs. Laura Albanese): Thank you. I'm sorry to—

Ms. Cindy Mitchell: I always run out of time. I've got a history here at this table of running out of time.

The Chair (Mrs. Laura Albanese): Maybe you can submit it to us? Would that be okay?

Ms. Cindy Mitchell: All right. But I've got a point to make, though.

The Chair (Mrs. Laura Albanese): Time has finished, and we're going to have an issue at the end of the day if we don't—

Ms. Cindy Mitchell: Can I make one last statement? I'm going to tell you there's a reason why you didn't get a printed copy of my presentation. It's because I wanted to take a stand for families, including my own, and tell you that there is an emotional and financial cost for us to come here. Most families, mine included, who come here cannot afford to pay for 35 copies for each of you, for this committee, as well as lose a day's work, as well as pay for support for their kids while they're here. So I will email you an electronic copy. Thanks.

The Chair (Mrs. Laura Albanese): We appreciate your deputation today.

ONTARIO ASSOCIATION OF CHILDREN'S REHABILITATION SERVICES

The Chair (Mrs. Laura Albanese): We will call on the Ontario Association of Children's Rehabilitation Services to come forward. Good afternoon. You may start as soon as you're ready.

Ms. Siu Mee Cheng: Hi. Thank you. Good afternoon. My name is Siu Mee Cheng, and I'm the chief executive officer of the Ontario Association of Children's Rehabilitation Services.

Ms. Louise Paul: I'm Louise Paul. I'm the chair of the board of directors with the Ontario Association of Children's Rehabilitation Services. From now on, we'll just refer to ourselves as OACRS. It's a little less of a mouthful for all of you to manage, and for us.

In my day job, I'm also the chief executive officer of the Children's Treatment Network of Simcoe York which provides CTC-funded services to children, youth and their families in Simcoe county and the regional municipality of York.

Ms. Siu Mee Cheng: Thank you for the opportunity to make a presentation before this committee. Our presentation will hopefully be within time. We have three parts to this presentation. We'd like to introduce ourselves as an association; and then spend a bit of time just talking to you a little bit about the views and concerns of our members, our stakeholders, and the clients and families who our members serve, in terms of their concerns with regard to the current system; and then provide you with five recommendations on what needs to be done in order to address these concerns.

To begin, the association has been the united provincial voice for the 21 treatment centres across Ontario for about 35 years, since 1978. Our aim is to ensure that children and youth reach their full potential. Together, OACRS members serve approximately 70,000 children and youth with special needs and their families on an annual basis, and half of these are children who have developmental disabilities.

The CTCs are a really cohesive group of service providers who provide a fairly comprehensive set of pediatric rehabilitation services within Ontario. They provide approximately \$275 million worth of publicly funded pediatric rehabilitation services, and they work both intersectorally and intrasectorally; that is, they work in partnership with education, health, municipal, social services and community-sector partners on interprovincial teams and interprofessional teams to meet the needs of children with disabilities, by providing integrated, inclusive and family-centred services.

On slide 4, you'll see a fairly comprehensive list of services that the children's treatment centres provide. Physiotherapy, occupational therapy, speech and language are some of the common services—also social work, as well as psychology, recreational therapy and other services, including some school health services and preschool speech and language. I will not go through the entire list.

That is the sum of OACRS and its members.

I'll let Louise talk about the current landscape and the concerns reflected by our members and stakeholders.

Ms. Louise Paul: I'm not going to go through an exhaustive list of what many of the issues are; I'm sure you've heard different perspectives on a number of the ones that I'll be referring to. I'm just going to highlight the key ones that were identified by our members.

Before I do that, I just want to pause to say, having listened to the amazing presentations from family members who came before us—I've worked in this field

for 35-plus years, and what still continues to puzzle me in many ways, and also sadden me, is that when I started 35 years ago, and continuing up to today—and I think I'll continue for a while longer—if there's one issue that families continually raise with us, it is the lack of simplified and coordinated access to a comprehensive range of services for their children and youth. It seems like something that we should have been able to figure out by now. Certainly that view of families was reflected in the fairly recent report that the then parliamentary assistant, Tracy MacCharles, presented to Minister Piruzza—certainly a very strong voice from families, and that was one of the key issues that they raised with her.

I don't think that having coordinated services solves all the problems. It certainly doesn't address all of the issues of caregiver burden, and other issues that we have around coordination amongst different service providers. But it will go a long way, I think, to helping families feel more comfortable moving through a system, being able to know what services are available, and having key individuals—whether you call them service coordinators or service navigators—as families need them, and identify the need to assist them in moving through this system.

1530

I just wanted to flag that one. It's not flagged in our slide deck but it's one that resonated for me when I was listening to the two previous presenters and one that our members have raised as well.

In terms of some specific concerns in terms of the lack of access to services, Siu Mee mentioned the range of rehabilitation services that the 21 CTCs in Ontario provide. We have a real issue, and continue to have an issue, around long, long wait times. That is obviously for children with developmental disabilities, who, as Siu Mee mentioned, make up 50% of our population that we serve, but also for the other 50% of the children we serve.

We have, particularly for areas like diagnostic assessments—I can speak to my own centre—a 12- to 14-month wait. That's for a child to get an assessment about what their diagnosis is. When you're dealing with children with developmental disabilities, which includes autism, that's an incredibly long wait time.

There are equally long wait times for essential services that are needed in a child's developmental years around speech and language, occupational and physiotherapy, and other services.

I'm sure the committee knows about the situation with residential services for children, and that is that historically the residential service places, or beds, for children with developmental disabilities have been, and continue to be, funded by MCSS. Children who have been in those beds as children have continued to age in place, and they are now adults. But the funding for those beds continues to come from the children's side of the MCSS funding envelope for developmental services. So when we have more children coming in through our system, primarily children with developmental disabilities—and as they become preteens and teenagers, they often have some-

times very challenging behavioural and anti-social behavioural issues to manage, and families can't care for them anymore—the lack of residential beds is really exacerbated by the fact that a percentage of that funding continues to provide residential supports for adults. Within the children's sector we have, yet again, long, long wait times for essential residential services for children.

In terms of diagnosis, I referred to that in a previous slide around the long wait times for getting specifically a diagnosis of developmental disability for a child. There becomes a huge issue for families when they get to the other end of that continuum and they're wanting to move into the adult system.

If you're a family and you have either had a fairly recent diagnostic assessment by a psychologist for your child, and that assessment covers both the cognitive and functional areas that are criteria for an eligibility assessment by the DSO, then you can begin planning with the DSO at age 16 or earlier for your child's transition into adult services. Once your child turns 18, you can hopefully get some access to direct service right away, but you will then go on to wait-lists for adult services, but as of the moment you turn 18.

However, for many families, they're in a different situation. Either they had a diagnosis a number of years ago, when the child first went into school, identified as having a developmental delay, identified what supports were needed around the educational system—for many children, that's the only kind of formal diagnosis they've had around a developmental disability. When they get to that age of 16 and they're looking at wanting to move into the planning for adult services, the previous diagnosis is either too old, not done by the appropriate individual—it has to be a psychologist—or it doesn't cover both cognitive and functional areas.

If those families have the ability to pay for a private psychological assessment—for the eligibility assessment—they will do that, and then they will be able to begin that planning process. If, however—and this is a situation for many of the families we work with—you do not have that funding capacity, you have to wait until your child turns 18, and then the regional DSO, if they still have funding available in that envelope for assessments, will put you on a list for assessment—for that functional assessment, that eligibility assessment. There could be a wait for that assessment, there's then a wait for the report, and then you can get on the list for services. So there is a bit of a two-tiered system here and certainly a real disadvantage for families who do not have the capacity to fund a private eligibility assessment to enter into the adult system. The DSO inadvertently becomes a real roadblock, not through intent, and it's not all their doing, because they are restricted from providing funding for that assessment until that individual turns 18.

One of the considerations could be that if they could move that age back to age 16, then that would allow those families and those children to start that planning process sooner. But at this point, they are restricted

because of the regulations, so they have no choice on that. That is obviously a major concern for us in terms of a roadblock to a really smooth transition into adult services for this population.

In terms of other parts of the fragmentation, we do want to highlight as well intersectoral fragmentation. I do want to preface this by saying that I think in the last two to three years, under the leadership of the Ministry of Children and Youth Services, we have seen much more interministerial collaboration and work. We work very closely with the Ministry of Health and the Ministry of Children and Youth Services, who fund us, and the Ministry of Education, obviously, during the years that children are in the educational system. We have seen a lot of movement around better coordination amongst the different sectors. However, there is still a long way to go, and there is no one provincial ministry that has direct, cohesive and comprehensive responsibility for all the policy and program service delivery for children and youth with developmental disabilities. I spoke to that a minute ago around the funding that still remains with MCSS for services for children with developmental disabilities, and then the funding and policy for children with developmental disabilities that falls under MCYS. So all the funding for the primary rehab provider for children's services for kids with developmental disabilities comes under MCYS, but a number of other services that those families access and that our service providers try to work in collaboration with are in a different sector, the developmental sector, which is primarily focused on adults, and tend to be within a different planning and service sector within local communities. It's inconsistent across the province, but they are not well integrated.

We want to also highlight family and caregiver issues. I will just hit on two.

In terms of dual diagnosis, one of the areas that we do want to flag for the committee is that—and I'm sure you've heard this from other presenters as well—the current service delivery system is really fragmented for children and youth with a dual diagnosis. Parents have to learn to navigate not only the children's rehab system and the school system, but they also need to learn how to navigate the children's mental health system. Because many of us have worked closely with our colleagues there, we know that within the children's mental health system there is often a reticence to serve children with a dual diagnosis because a lot of children's mental health providers don't feel like they have the skills and the competency to do that.

In terms of access to Special Services at Home and respite funding, I honestly don't think I could add much to the conversation, particularly from the speaker two speakers ago, who I think very eloquently addressed what the issues are around being able to access that type of funding. I would just say, though, that we do know that there is lots of evidence that shows that low-cost programs like Special Services at Home and respite funding can really, really help maintain families' quality of life and their resiliency and can in many cases avoid the need for out-of-home placement.

Caregiver burden: I think I, as well, am going to say that we would echo what has been said by the past two speakers and don't have anything to add at this point. We do have some recommendations, but I think that they said all that really needs to be said about that issue.

1540

In terms of transitional support for families and caregivers, there's a great quote on this slide from Ivan, who's a parent, who says, "I don't understand why my child (who is 17) has to get an assessment again to determine a developmental disability diagnosis for adult services if my child already was told by the school and others (i.e., CTC) that my child has a developmental disability." And we all know that. It just reinforces the comment I made earlier about the challenge with assessments at the point of transfer into the adult system through the DSO.

We know that children and youth with disabilities require supports to seamlessly transition between developmental stages, including stages throughout childhood and from the children's system into the adult system. I've spoken to this point really around the transition into the adult system. There is also a gap when children transition from preschool and community-based care into the school system. Children's treatment centres are the primary provider of rehab services up until a child turns age four or five, depending on when they go into school. Then, the funding and the authority to provide in-school rehab services shifts to the Ministry of Health and the community care access centres, which provide services through contracted providers, and those individuals provide the rehab services: OT, physio, speech and language, feeding—if that support is needed—in the school setting.

At this point, only five of the 21 children's treatment centres have those contracts or provide services within the school setting under the auspices of the local CCAC. So what happens is, a family who has been having pretty good service for the most part—coordinated, comprehensive service delivery through the children's treatment centres—moves into the school environment, and that therapist or those therapists don't follow that child through the school, with the exception of the five CTCs that provide those services. They have to establish new relationships. It's a different type of service that is provided. It's much more time-driven. There is no capacity for the therapist providing that service in the school to go and see the child in the home environment and in other community environments, like they can when they're with the CTC. So there's a huge disruption and rupture for families. They're not only trying to adjust to a new setting for their child, but they also do not have that continuity of service delivery in the rehab area. That's a huge concern for us in terms of continuity of coordinated and appropriate rehab services.

The Chair (Mrs. Laura Albanese): You have about a minute—

Ms. Louise Paul: Oh, gosh.

The Chair (Mrs. Laura Albanese): Sorry.

Ms. Louise Paul: You know what? I think I've covered most of this stuff. I didn't realize I'd wandered on for so long. I'm just going to turn it over to Siu Mee for a summary of our recommendations.

Ms. Siu Mee Cheng: All right. Thank you. A minute left; I will gallop along then.

We do have five recommendations. The first is ensuring that there is a whole-of-government approach to addressing the needs of children and youth with developmental disabilities—so the Ministries of Children and Youth Services, Community and Social Services, Municipal Affairs and Housing, Health and Long-Term Care, Education, and Training, Colleges and Universities—to build a comprehensive framework and approach to addressing the needs and service needs. This includes addressing moving relevant policy development and funding of relevant services over to the Ministry of Children and Youth Services. As well, the Minister of Children and Youth Services should, when they're advancing the mental health transformation agenda, include the rehabilitation services sector in their discussion tables.

The second recommendation is investment in services for those with developmental disabilities, so greater investments for rehabilitation services and other services for children and youth. This includes considering investments in integrated rehab services in the school setting, for instance, in the full-day kindergarten learning environment.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Siu Mee Cheng: I'm up? All right.

The Chair (Mrs. Laura Albanese): Sorry.

Ms. Louise Paul: No, I was the one that went on too long.

Ms. Siu Mee Cheng: Well, we are making a written submission. Thank you.

The Chair (Mrs. Laura Albanese): But we do have your deck, and we will make sure to read it.

Ms. Louise Paul: Yes, thank you.

Ms. Siu Mee Cheng: Thank you.

The Chair (Mrs. Laura Albanese): Thank you so much for coming here today and presenting before the committee.

JUSTICE FOR CHILDREN AND YOUTH

The Chair (Mrs. Laura Albanese): Now we call on Justice for Children and Youth to come forward. Good afternoon and welcome.

Ms. Mary Birdsell: Good afternoon. Thank you.

The Chair (Mrs. Laura Albanese): If you could please state your names and titles before you begin your presentation for the purposes of Hansard recording.

Ms. Mary Birdsell: Absolutely. Thank you. My name is Mary Birdsell and I am the executive director of the legal clinic Justice for Children and Youth.

Ms. Samira Ahmed: My name is Samira Ahmed and I am a staff lawyer at Justice for Children and Youth.

Ms. Mary Birdsell: We very much appreciate the opportunity to come and to speak with you today. We

apologize; we don't have written submissions for you at this point. We were informed of the timing on Friday, and although it would have been ideal for us to have been prepared much ahead of time, we were not and we had to rearrange our schedules to be here, but we really wanted to do that in recognition of the significance and importance of the issues that you are addressing.

We know that you will have heard from many knowledgeable and extremely well-informed parties, and we want to try and focus our submissions today on things that are relatively connected to the legal issues that we see.

While we appreciate the opportunity to be here and we know that you've had many professional people here, we hope that in the creation of your strategy, recommendations and report and in any planning and strategizing that you do, you will commit some resources, including time, to consult directly with young people who are affected by the issues that you're considering and who are living through the subject matter of your inquiry.

I'm going to ask Samira to introduce Justice for Children and Youth to you briefly, and then we'll address our submissions.

Ms. Samira Ahmed: Justice for Children and Youth is the only organization in Canada, and one of a few in the world, that is exclusively focused on the legal rights of children and youth. This allows our clinic to offer a highly specialized voice on the issues affecting youth and their legal rights.

We strive to promote youth dignity and the rights of children and youth. Voice and empowerment are important tenets of our mission, and this is the most effective way, in our opinion, to protect and preserve the rights of children and youth, and allows youth, with the tools and context, to speak for themselves as individual rights holders in society.

At Justice for Children and Youth, we have lawyers who represent and advocate for youth who are under the age of 18, as well as for homeless youth who are under the age of 25. We are a specialty legal clinic that is funded to provide services to youth across the province. We regularly and routinely have contact with youth or parents of youth who are struggling with mental illness or developmental disabilities. We receive phone calls from youth who are experiencing educational issues, criminal issues and child protection situations. These situations are often as a direct result of their vulnerabilities due to their mental health issues or their developmental disabilities and, at times, both.

These youth are contacting our office for assistance and are often not receiving adequate support and/or treatment for their mental health issues or developmental difficulties.

Ms. Mary Birdsell: I just wanted to echo something that you heard from the previous speaker with respect to the simplified and comprehensive access to supports and services for families across Ontario. I would agree that in the almost 20 years that I have been working in the field, it does seem to be a perennially frustrating issue that

there isn't a simplified place to go to get comprehensive access. I often think that if we seem, as a broader society, to be able to coordinate services to analyze the rocks on Mars, surely to heaven we can create coordinated and simplified access for these vulnerable people in our communities.

I wanted to recognize as a general matter that the young people to whom we offer services fall across a very broad range of their needs with respect to mental health services and developmental needs and the complexities that come with dual diagnosis, and that services need to be responsive and aware about the range of needs so that they can adapt to individualized circumstances. I would say that as a general matter the ability to individualize services and supports is an important part of any comprehensive strategy.

1550

I would say also that, generally speaking, the questions of mental health and developmental disabilities are very, very common in our client population. They are issues that affect almost every young person that we come into contact with.

We wanted to address four specific areas that persistently arise in the intersection between social and legal contexts for these young people. One is the child protection gap, and I will talk about that in a little bit more detail. The other is education issues. The third is transitional issues. Fourth, I just want to touch very briefly on the criminal justice system issues.

With respect to child protection, one of the areas of debate, not only inside our office but with many people with whom we come into contact, is the question of special-needs agreements under the Child and Family Services Act. As you may or may not be aware, there is a context in child protection where special-needs agreements are available in the legislation.

In 2001, there was a ministerial directive essentially putting an end to the provision of special-needs agreements where there are no other child protection concerns. Really, what this creates is a circumstance where a family can care, wants to care and has personal resources to care for their children who have mental health or developmental disabilities, but they don't have the other resources that they need to provide adequate services, so they're coming to child welfare to say, "I can't do it without your help." What child welfare has said now is, "Well, you don't present a protection concern; you're a loving, caring parent," but the reality is families cannot cope with the layers and layers of needs that might be available. Yet, what the ministry has said is, "We are not going to offer special-needs agreements in these circumstances."

I'm going to offer you just a very small vignette to illustrate this. We're trying to assist a family who had a newborn baby who was on a ventilation tube and whose health needs meant that they needed to have 24-hour, eyes-on observation. The person who was caring for this baby was a single mother with very few social connections in the community. She was really, really stuck. The

children's hospital didn't want to discharge this baby because they felt that the parent couldn't care for them. Child welfare was unwilling to provide special-needs agreements and supports, and through the other kinds of access to services that this parent could access, there wasn't sufficient support to enable that baby to have 24-hour, eyes-on services. One of the commentaries was, "Well, we don't know whether this baby has developmental needs or not." That's just a simple example of a huge gap that's created in part by this question of child protection. There are many, many other examples that I'm sure you can imagine with respect to older children.

In our submission: Ontario must be able to provide adequate, appropriate and accessible services that are designed to keep families together, even in circumstances where we don't fully understand the nature of the disabilities that children are experiencing. I think that when you've got severe, complex special needs in the health context, those kinds of children need to be addressed in any comprehensive service. We understand the ministry directive, but we think that this removal of child welfare services really leaves an enormous gap for families who, while they want to provide care, may not have the resources that they need to have. Perhaps the answer is to create an individualized special-needs agreement model that is inter-ministerial between health, education, MCYS and MCSS, and perhaps there are other ministries as well that might be involved. Our proposal would be that they be mandated to ensure that there are appropriate educational services and supports, appropriate care and treatment resources available and appropriate supports for families, and that all of these together ensure the optimal health of young people.

I'm going to come back to this later, but we'd like to identify that, in fact, Canada and Ontario, who are signatories to the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, are mandated to attend to these issues.

This is somewhat repetitive, but there needs to be one place for families to go where members at the table are empowered to make decisions. If there is an inter-ministerial service coordinator, they have to be empowered to make decisions, including financial decisions, and they need to have access to the various resources that the various ministries have at their disposal.

The other comment I'd like to make with respect to the Child and Family Services Act and child welfare services is that recently the Legislature is considering—it will go to third reading, we hope, when the Legislature is up again—Bill 88, which will provide some voluntary services to 16- and 17-year-olds.

One of the things that we see, especially in the homeless young people whom we offer services to, is what really would amount to child protection needs. Definitely mental health needs are very extreme, and developmental disabilities are also very present in the street youth population. Bill 88 will go some distance, we hope, to offering voluntary services to these young folks who have really fallen through the cracks in the most obvious

ways, but we're still concerned about what happens to them when they turn 18 and what the quality and nature of these services will be. So I think these issues are still very much on your platter, even if that bill passes.

I'd like to move now, as the clock ticks by, to talk briefly about education issues and in particular special education issues, which are routinely engaged for the young people with whom you are concerned. As you know, special education supports are a matter of human rights. We are obligated to provide special education supports to young people who need them, but I would say that children, young people and their families are at the mercy of limited resources. In particular, smaller boards of education in more remote and rural communities, and their students, are disadvantaged by the small size of their boards.

Of course, this is a massive problem—and I'm glad that you are the brain trust who need to struggle with the details—but this can't be the reality in Ontario: that if you live in a place where you are in the midst of a large board of education, you might have access to services, but if you are in a smaller or more finely dispersed board you can't access services at all.

One of the difficulties that arises in this context is that school boards and school administrators wind up using disciplinary tactics as a fallback for a lack of services, so that young people who struggle with developmental issues and behavioural issues that arise in that context are left suspended, expelled and excluded from school for the very reasons that make them worthy of the human rights supports that they need.

Again, to use a somewhat mundane example, if you have a young person with a developmental delay, maybe autism, or many other kinds of things, who struggles with the management of simple behavioural things—outbursts, anger or frustration—when they act out, they wind up getting suspended or even expelled, even at the elementary school level, when what they really need are the supports to help them to learn to cope in the school context. These are fairly serious human rights violations, in our view, and they're massive weights to leave on families who are already struggling with the realities of children who are struggling.

The other thing I would say in this regard that I think is important to recognize is that school disruption only serves to further disadvantage students who are already struggling in the system, and that the societal costs of this are unacceptable and avoidable. Of course, while providing school resources may mean money, I think that, in the overall analysis, we are certainly much better off to provide those kinds of resources when children are young and still in school, and save ourselves the sad outcomes for young people who are excluded from schools.

One of the solutions that I would offer to this—and this is a small solution, but I think it is very important—is that school boards and school administrators must be educated about their human rights obligations and their Education Act obligations so that they understand the difference between disciplinary responses and human

rights responses to children with special needs. One of the things that might be difficult to do in some ways but would be fantastic in other ways is if there were mobile services to support remote and rural communities in terms of the kinds of things and special education supports that young people need.

1600

Another education issue that is distinct but is very important is the issue of assessments. I'm sure it has come up for you repeatedly, but it is a huge problem across the province. Even large school boards struggle with one-, two- or even three-year waiting lists to get psycho-educational assessments for students. The previous speaker spoke about assessments more generally for developmental needs, and of course those are very important issues. But even just to get a psycho-educational assessment might be a huge, long wait, if not near-impossible. This cannot be, because we can't provide appropriate and meaningful supports unless we have a good sense of what's going on. It's an area that needs to be remedied immediately.

I wanted to speak to you about transition services. Again, as the previous speaker noted, there are a number of transitions that occur for children and youth from infancy to adulthood in the context of developmental disabilities and mental health. I want to speak specifically to the question of transitioning from youth to adulthood. I would say that, in our experience, it's a terrible stage for young people and their families and that we need to eliminate the age-based bright lines that exist from services and supports in one context to services and supports in another context, so that there's always an overlap in services and supports that we provide and so that no family or young person is left hearing, "The day you turn 18 is the day you have to jump into this next ether that you haven't been able to access at all prior to that moment when you arrive there." It creates an impossible situation where you wind up being potentially homeless with developmental disabilities and mental health issues and suddenly being cut off from all of the supports that you may have had up until that time. In our view, we need to plan for and coordinate the overlap of services so that there's actually a full-on expectation that services and supports will overlap and that one set will not end until the other one has already been implemented and working and functioning. We would suggest that there be a legislated duty to implement smooth transitions.

The other thing that I would say in support of this, and I realize my time is probably running short, is that we have not always known the depth and extent to which brain development does not magically change and that in fact childhood and adolescence, in terms of brain development, continue definitely into your 20s and probably into your mid-20s, and that this is multiplied as an important issue for young people with mental health and developmental disabilities.

I wanted to speak very, very briefly about the criminal justice system. I would say that in our experience, the criminal justice system is often used as a mechanism for

addressing the behaviour of young people with developmental disabilities and mental health issues. I couldn't try and express to you more strongly how inappropriate I think this is and how ill-equipped it is to deal with the complexity of the issues that these young people face. I think people turn to it when they feel frustrated and at a loss for what to do, but it's like going from one place where people are knowledgeable, educated and steeped in the issues to another place where people are not knowledgeable, are not educated and are not steeped in the issues. Not to sound like a terrible cynic, but the criminal justice system is designed to be responsive by executing—pardon the use of that word—by implementing punishment for wrong deeds done to people who understand the nature of their behaviour. It's not really designed to address developmental and mental health issues. Of course, it works hard to try and address those realities because the criminal justice system as a system knows that those things exist and that they're important, but that is not the place for young people with developmental delay and mental health issues.

The Chair (Mrs. Laura Albanese): You have about 30 seconds.

Ms. Mary Birdsell: The other thing that we would like to commend to you in terms of strategizing and going forward is that a coordinated approach to researching the needs of young people with developmental disability and mental health issues across the province would be a very fruitful task for the government to take the lead on. They have many resources at their disposal, and, of course, access to brilliant academics who I'm sure could provide fruitful commentary.

Thank you very much for your time.

The Chair (Mrs. Laura Albanese): Well, thank you for this thorough presentation. I apologize that I have to be so draconian with the times, but that's what I need to do as Chair.

Ms. Mary Birdsell: We understand.

The Chair (Mrs. Laura Albanese): Thank you so much.

ARCH DISABILITY LAW CENTRE

The Chair (Mrs. Laura Albanese): We'll now welcome ARCH Disability Law Centre. Good afternoon. Welcome to our committee.

Ms. Kerri Joffe: Thank you very much.

The Chair (Mrs. Laura Albanese): If you could please state your name and title before you begin your presentation, that would be much appreciated.

Ms. Kerri Joffe: My name is Kerri Joffe. I'm a staff lawyer at ARCH Disability Law Centre, which is a legal clinic, like Justice for Children and Youth, but ARCH is dedicated to providing services specifically to people with disabilities in Ontario.

With me today are Tebasum Durrani and Maija-lisa Robinson. They are both law students at Osgoode Hall Law School, and they are both completing internships at ARCH. They've come to assist me in presenting to you today.

I'll just tell you very briefly a little bit about ARCH, for those committee members who don't know us.

As I said, we're a legal clinic. Our mandate is to defend and advance the equality rights of persons with disabilities in Ontario. We do this in a variety of ways. We provide legal information and advice directly to people with disabilities throughout the province, including people who have developmental disabilities. We also represent people with disabilities, including people with developmental disabilities, in litigation at all levels of tribunals and courts.

We regularly work with people with developmental disabilities, their families and support agencies to conduct community development initiatives to support the community, and we do quite a bit of public legal education around human rights and disability rights for people with intellectual and developmental disabilities.

The submissions that we are going to make to you today are based on and draw upon that body of work and the context that we have very regularly with the community. We have prepared a written submission, which has been emailed to the Clerk this afternoon; it's not here, but you'll have it, I'm sure, to consider.

This afternoon, we'd like to focus on three key issues that we see as really important for strengthening and improving the developmental services sector.

The first is the need to include substantive rights for people with developmental disabilities in the law that governs developmental services and in the sector more generally.

The second issue is the need to promote and strengthen the right of persons with developmental disabilities to make their own decisions. We also refer to that as the right to legal capacity.

The third is the need to establish an accessible and independent complaint mechanism to ensure that developmental services and supports—and hopefully direct funding as well—are accountable to people with developmental disabilities.

I'm going to turn it over now to Tebasum and Maija-lisa to flesh out those three points.

Ms. Maija-lisa Robinson: Hello. Since 2008, ARCH has made several submissions regarding the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act and its accompanying regulations. I'm going to simply refer to that as the social inclusion act.

It continues to be ARCH's position that the legislation should include a clear statutory framework establishing substantive rights for people with intellectual disabilities who receive developmental services. The obligations on service providers set out in the quality assurance measures are designed to ensure that service agencies are accountable to the ministry for the quality of services and supports that they provide to people with disabilities. However, there is little in the regulation to make services and supports accountable to the individuals who receive them.

1610

In drafting the social inclusion act, it was the government's intention to transform the developmental services sector. Six years later, this committee is hearing from service providers and other organizations, as well as from families, about the serious problems that they face and the current crisis within the system.

It is ARCH's position that, in order to fulfill the government's stated objective of transforming the developmental services sector, people who receive developmental services must have rights. Enshrining rights in legislation sends a strong message that the government is committed to upholding the dignity and full participation of people with intellectual disabilities as equal citizens in society.

The provision of rights is empowering. It enables people who receive developmental services to access legal tools to address concerns they may have about services, instead of relying solely on the government to ensure that service providers comply with the act. The inclusion of rights is a fundamental step towards transforming the role of people with disabilities in the developmental services sector from passive recipients of care to active consumers of services who are accountable to them.

The unique circumstances of people with disabilities who receive developmental services are not addressed under Ontario's Human Rights Code or the Canadian Charter of Rights and Freedoms, which provide fundamental rights and protections but not rights specific to the developmental services sector. While people with disabilities are protected against discrimination and have the right to equal protection and benefit under the law, they have no rights regarding the quality and types of services and supports they are entitled to.

Let me give you an example of the type of situation that ARCH has dealt with. A woman who has lived in the same group home for more than 20 years is told that she will be moving to another home in a different part of town, far away from her family and her community. She has no input and no role in the decision-making process regarding a fundamental right that we take for granted: where and with whom she will live.

Some examples of the types of service rights that could be included in the legislation are:

- freedom of choice regarding activities of daily living, including decisions about food, clothing, personal appearance and participation in activities;
- the right to enjoy personal privacy, including expectations of daily living such as the right to have a private telephone conversation and the right to receive visitors of the person's choosing;
- the right to legal capacity; and
- the right to have personal decisions respected.

Including rights in the social inclusion act is important for several reasons. Symbolically, it demonstrates that the humanity and dignity of people with intellectual disabilities is not merely recognized in words but in substantive rights that people can use to improve the quality of their

daily lives. This is linked to quality assurance measures, as the provision and enforcement of rights for people with intellectual disabilities will undoubtedly lead to an improved quality of developmental services.

Practically, including rights in the legislation is the first step toward creating a culture of rights within the developmental services sector, thereby increasing the possibility that people with disabilities will have more autonomy, control and self-determination over their lives.

Finally, the inclusion of service rights in the legislation will ensure that people with disabilities and service providers have similar expectations and standards. Adopting rights in the legislation would provide much-needed uniformity, ensuring that these rights apply to everyone who receives developmental services, regardless of which agency or support worker provides the service.

An important and related rights-based issue that I would like to draw your attention to today is legal capacity and the right to make one's own decisions. Under the law, capacity is presumed. Capacity is both issue-specific and dynamic. A person may be capable of making one kind of decision and not another, or may be capable at one point in time and not another.

Unless an adult is found to be incapable, they have the right to be informed and to make their own decisions in regard to every aspect of their life. This includes the right to make their own choices about everyday matters and matters related to developmental services.

The social inclusion act attempts to recognize that people with intellectual disabilities are entitled to live in communities of their choosing and participate as equal citizens in community life, yet there continue to be barriers that impede the realization of these entitlements. One of these barriers is the difficulty establishing a culture in which service providers and community members respect the right of people with intellectual disabilities to self-determination. ARCH regularly hears about and deals with situations in which service providers, family members and others assume that a person lacks capacity to make his or her own decisions simply because he or she has an intellectual disability or uses developmental services. Service providers may require family members to provide written consent to allow a person with a disability to participate in an outing or a community activity. Service providers insist on getting this permission even though the person with the disability is an adult who can and is entitled to make his or her own decision about participating in the outing. This is just one example of the way in which people with intellectual disabilities are denied the right to make their own decisions.

The social inclusion act is silent on the issue of capacity and does not protect autonomy of persons with intellectual disabilities. I would refer you to ARCH's written submissions for specific provisions and recommended amendments to the legislation.

A key change that can be made to strengthen Ontario's developmental services system is to ensure that laws and

policies promote and protect individuals' right to make their own decisions. The legal presumption of capacity should be reflected and incorporated into the social inclusion act. Those who work in service agencies, DSOs and other developmental service providers must receive training on capacity law, the importance of supporting individual autonomy and how to accommodate individuals with disabilities to enhance their ability to make their own decisions. Thank you.

Ms. Tebasum Durrani: Good afternoon. Just as clearly articulating rights in the social inclusion act is crucial to promoting the empowerment of individuals with disabilities, so too is the addition of a process that ensures accountability and enforcement of those rights. Rights would be meaningless without a transparent and independent process to ensure that they are protected.

As such, ARCH recommends that the strategy for developmental services incorporate a rights-enforcement framework that is external from the service provider complaints process. The lack of such a mechanism within the legislation as it stands is problematic because there is no defined process for individuals to make additional complaints about the services that they receive to a neutral body that is external from the service provider.

People with developmental disabilities should have the right to a process that can be used to raise concerns about the service provision they receive and to recommend changes to promote enhanced accountability and quality assurance for those services. This is essential in order to ensure that individuals are provided with an avenue to assert their rights to receive developmental services in a safe and respectful manner.

At present, service agencies are mandated by the social inclusion act to have procedures to address complaints. Section 26 of the act requires agencies to have written procedures for initiating complaints to the agency and how they will handle those complaints. However, ARCH submits that there are challenges associated with the effectiveness of such internal mechanisms. While the existence of these processes is important, they should not be the last step for individuals in terms of asserting their rights as recipients of developmental services.

Due to the nature of supports that some people require and the environment in which those services are delivered, many individuals with disabilities fear abuse or being threatened or retaliated against if they file a complaint about the services they receive. Depending on their unique needs, people with intellectual disabilities may require support for activities of daily living, and this dependence can often enhance the inherent power imbalance that exists within the relationship between the person with a disability and his or her support worker. Individuals must work hard to maintain good relationships with their service providers and others upon whom they rely for daily assistance. Making a complaint about a support worker or raising concerns about services received can threaten these key relationships.

Further, individuals may fear being reprimanded by their support worker or being threatened with cuts to their

benefits or privileges. Some agencies may require that individuals first raise their complaints with their support worker, against whom the complaint is being made. Again, fear of jeopardizing the relationship means that many individuals choose to stay silent.

1620

Finally, the neutrality of the process should be a priority given that current complaints processes are internal to a service provider agency. While the development of these internal mechanisms is important, ARCH submits that an additional layer of oversight is necessary to promote greater accountability and ultimate transparency.

In order to address these concerns, ARCH recommends that the strategy for developmental services includes the creation of an independent body that would receive and evaluate complaints. The objective is to give individuals a voice in terms of the services they are receiving and to ultimately enforce their rights to quality services. Ideally, its membership would be comprised of individuals who have expertise and experience in the developmental services sector and an understanding of the legislative framework surrounding service provision.

Any model will need to consider the necessary level of support that complainants would require in order to effectively pursue a complaint. ARCH recommends that consultations be conducted with persons with intellectual disabilities on what model would be most appropriate and what supports they may require to navigate such a process. This may include examining an advocate's office model, an ombudsman model or a more adversarial process with appropriate supports for individuals with developmental disabilities.

Finally, individuals who receive developmental services should be provided with information about the complaints mechanisms in a way that is accessible to them. The human rights principle of accessibility mandates that complaints mechanisms be designed to ensure that people with disabilities can access them and engage with them effectively. If the processes are too complex or legalistic, this will create additional barriers to accessibility, thereby undercutting the very purpose of these mechanisms. To remedy this, ARCH recommends developing resources that explain the complaint body's role in clear language, as well as promoting public education about the existence of this body and its purposes throughout the community.

The provision of ongoing support for the duration of the process of filing a complaint is also essential to maximizing accessibility and ultimately enhancing the effectiveness of any such process.

Any procedures that would require the drafting or filing of complex documents and the presentation of cumbersome legal arguments should also be modified with the goal of enhanced accessibility and ultimate flexibility for individuals. Thank you.

Ms. Kerri Joffe: How much time do we have?

The Chair (Mrs. Laura Albanese): You still have two minutes.

Ms. Kerri Joffe: Great, okay.

Before we ask you if you have any questions for us, I just want to echo the submissions of Justice for Children and Youth on the issue of the committee making time to consult with people who are actually affected by developmental services, people who receive developmental services. I know they work primarily with children and youth. We work with children and youth with disabilities, but also adults with disabilities. I would comment to the committee to really think about a meaningful consultation process for people who receive developmental services, which likely would look quite different from the hearings that have been held to date. We, at ARCH, are happy to consult with the committee on what that process may look like if that's something that people are interested in.

The Chair (Mrs. Laura Albanese): I want to consult with the committee members, but we have had some present to us as well in the course of our hearings, and we have visited some centres, just to let you know.

In any case, I would say it's more a comment more than a question. If it's a question, it's really brief. We're down to a minute and a half. Ms. Hunter.

Ms. Mitzie Hunter: Mr. Balkissoon.

Mr. Bas Balkissoon: Thank you for being here and thank you for your presentation. It's well prepared. Thanks a lot.

The Chair (Mrs. Laura Albanese): Ms. Elliott?

Mrs. Christine Elliott: Thank you for being here, and thank you for the work that you do on behalf of people with disabilities. It's really, really important, and we have taken note of the legal issues you've presented to us and look forward to your presentation in written form. So thank you very much.

Ms. Kerri Joffe: Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: I looked up the Ontario Human Rights Code as we were speaking and saw disability there, so I'd be very interested in a presentation about why that process isn't sufficient, because I know that Huronia is a classic example. The Ontario government has been sued, and successfully. So if in your presentation you've got more information about that, I would be very interested.

Ms. Kerri Joffe: We do have a bit more in our written submission. Do I have a minute to address the comment?

The Chair (Mrs. Laura Albanese): You have 30 seconds.

Ms. Kerri Joffe: Thirty seconds. Okay. I'll try to address it very briefly. The Ontario Human Rights Code and the charter both address the legal issue of discrimination, so discrimination on the basis of disability. The kinds of issues that we see people coming to us with, people who receive developmental services, would not be able to be presented in an Ontario human rights tribunal process or in a charter challenge before a court, because those issues—it's very difficult to characterize them under the legal rubric of discrimination. They are issues that are related more to quality of services and complaints about the types of services that are received, lack

of services, lack of choice, people's rights to make their own decisions not being respected. Those are quite different from our legal understanding of what constitutes discrimination, which is essentially being treated differently or negatively on the basis of your disability.

The Chair (Mrs. Laura Albanese): Thank you very much.

Ms. Kerri Joffe: Thank you.

MR. BARRY STANLEY

The Chair (Mrs. Laura Albanese): Now we call on Barry Stanley to come forward. Barry Stanley? Good afternoon.

Mr. Barry Stanley: Good afternoon, Madam Chair.

The Chair (Mrs. Laura Albanese): Welcome to our committee. You will have up to 20 minutes for your presentation.

Mr. Barry Stanley: I'm sorry. How long?

The Chair (Mrs. Laura Albanese): You will have up to 20 minutes for your presentation. If it's any shorter, that will leave time for questions and comments.

Mr. Barry Stanley: Thank you, Madam Chair. I'd like to thank you and the committee members for allowing me to make this submission.

The actual written submission, which I think you have in front of you, is quite extensive, so I don't intend to go through it all, because that would take up too much time. So the relevant points that you've asked for in your mandate are what I'm going to stress.

I'm speaking, basically, on behalf of those who are afflicted with fetal alcohol spectrum disorder and the families who support them. As you'll see, I am a parent myself, and I've been very actively involved in treatment and diagnosis prior to retiring at the age of 71 three years ago.

So I'm going to start on what is actually—I regret they're not numbered, but it's the seventh page. I'll read it and, if I have time, make comments. I hope there's time for questions.

Prenatal alcohol exposure to the developing fetus results in varying degrees of impaired brain function that are measured by neuropsychological testing. These neurodevelopmental disabilities are permanent and result in involvement by the individual with all the government agencies that you are considering here today.

Each assessment is a unique profile of the intellectual abilities of the individual and is essentially valid throughout their lifetime. There are some exceptions, but essentially that's true. We have in Canada the Canadian guidelines for the diagnosis of FASD, FAS and ARND, and you have a copy of those guidelines. These terms are designations given by the Canadian guidelines for the neurodevelopmental disabilities due to prenatal alcohol exposure. These guidelines include the set of psychological tests and the results required to make the diagnosis. I would refer them to you. As I say, you have a copy of the guidelines there.

It has been known since 1996 that if the diagnosis of FASD is made in early childhood and the appropriate

measures taken, then the child will have less issues with schooling, the law, addictions, work and social interactions, most of which you are addressing today. The appropriate measures require recognition and understanding of FASD by all the agencies that you are considering.

1630

In Ontario, assessments are difficult to obtain due to poor funding and lack of appreciation of their importance. Consequently, FASD is underdiagnosed, with often tragic consequences to the individual and great expense to the province.

FASD—and I would like to emphasize this, please—is the only medical diagnosis that is denied in Ontario because of lack of access to the required psychological assessments and the paucity of diagnostic facilities. There is no medical condition that I'm aware of as a physician where the diagnosis is denied, in distinction, of course, to certain treatments, which are expensive and there is issue about. But the actual diagnosis is not denied except if you're FASD.

Since 1996, it has been apparent to those researching FASD that the IQ is inadequate and misleading as a tool for measuring the abilities of children who have been exposed to alcohol prenatally, yet to a varying extent, Ontario's public agencies rely on the IQ as a measure of intellectual ability. This results in the exclusion of many who need assistance, especially those with FASD.

The human brain is the most complex system known. The effect of prenatal alcohol exposure on the developing brain is ubiquitous and variable, within the range—and again, I stress this—of the IQ from extremely low to superior. Yet even the intelligent, as measured by the IQ, have chaotic lives, with various combinations of cognitive, information processing, memory and adaptive and executive functioning disabilities.

Sadly, most of those with FASD—children and adults—are seen as selfish, wilful, defiant and even evil, as stated to me by a crown prosecutor recently, when in fact they are desperately doing their best to make sense of their environment and the circumstances they find themselves in. In addition, their caregivers are usually blamed for the behaviour of the affected children. This often results in loss of the child and sometimes criminal charges against the caregiver, again with tragic consequences and hidden costs to the province.

Some 94% of those diagnosed will receive other diagnoses from the DSM, often multiple diagnoses; I've seen as many as six. It is important that the role of the DSM-5, which is the recent edition, is fully understood by our legislators. The Diagnostic and Statistical Manual is published by the American Psychiatric Association and is used throughout Canada by psychiatrists, pediatricians and psychologists. It includes mental health, developmental and behavioural diagnoses—diagnoses that enable access to government, public and private agencies for relief, awards and compensation. It's a vital document or book—they call it the bible of psychiatry. It's vital in the administration of all or most of your agencies. But the

DSM-5, as in previous editions, does not include FASD, FAS or ARND.

This is one of the reasons why those with FASD and the families that support them have been denied what is rightfully theirs. The only way this gross deficiency can be rectified is for legislation to specifically include FASD as meeting the requirements for funding etc. by all government agencies that are involved.

I'm now going to go on to the items that you specified—suggestions and issues that you identified etc.

The elementary and secondary educational needs of children and youth—and I'm mostly referring, of course, to FASD, but I should say that it applies to all cases of intellectual disabilities. It's just that FASD is excluded so often. Children diagnosed with FASD need to be designated as exceptional, as in the acts governing education in Ontario. Children diagnosed with FASD need to be included in special education services.

The screening tools for FASD should be part of the training and the diagnosis pursued when appropriate.

All teaching and support staff should have training in FASD and be familiar with the psychological profile of the individual child.

Funding for psychological assessments should be a priority for all children with developmental disabilities of FASD. This is important in terms of costs, because the psychological assessments are one of the most expensive parts of the diagnosis and one of the reasons why the diagnosis often cannot be verified or pursued. What I maintain is that if this psychological assessment is passed and used by different agencies, then the virtual cost, of course, goes down, right? If it's only used in one agency and then repeated as necessary, then the cost goes up. So I say the psychological assessments from other sources, if adequate, should be used when available.

Behavioral issues need to be seen for what they are: a consequence of neurodevelopmental disabilities and not willful choices.

Programs for FASD need to be implemented universally. They should be based upon current research and be regularly updated.

A big issue is multiple schools, or schooling. FASD families are prone to move a lot. This means the children will often attend numerous schools over short periods. In addition, those children diagnosed FASD in CAS care—and there are many of them—often have multiple foster placements, resulting in a changing of schools. This, again, is due to lack of training and understanding of FASD and compounds the problems of education. Every effort should be made to keep the child in a stable school and home environment for optimum results.

Another important point: Other diagnoses from the DSM-5 should not exclude awareness, screening and diagnosis of FASD. On the contrary, such diagnoses should be a red flag for the diagnosis of FASD. Unfortunately, the opposite usually occurs once another diagnosis is made or efforts to explore the possibility of FASD are abandoned with, again, very negative results, as my case study at the end, which you may not have time to go through, illustrates.

Continuous two-way communication between the school and the caregiver is needed for the child to make optimal progress.

Moving on to the next issue, the educational and workplace needs of youth upon completion of secondary school: All transitions are difficult for those with FASD. While many do not complete school, for those who do the transition into the workplace can be especially difficult. Many will not be able to maintain employment—don't say they don't want to work, which is the usual thing—my son had 20 jobs in the first 10 years after leaving school.

Ontario Works needs to screen for FASD and refer for diagnosis when required. Work guidelines need to be developed by Ontario Works and shared with employers. I've got some suggestions here; I just don't want to run out of time. The complexity of the work and the degree to which it is multi-tasking depends on the intelligence of the individual. An intelligent FASD person can do a complex job; however, the following need to be in place, as a reflection of their disabilities:

- consistency: no significant variations, no unexpected changes or interruptions to the routine. Hours should be consistent. It may be best to avoid shift work. Part-time work may be preferable; no overtime, although some flexibility in terms of starting time could be best;

- no increase in the responsibility or workload, no matter how efficient they may be. Depending on the sleep patterns, night work may be best;

- no team work. FASD individuals certainly can, and may work around others; however, the work that they do should not require input from others. Likewise, other persons' work should not require input from the individual with FASD.

1640

They should only have to report to one person who has an understanding of FASD.

Depending on the type and degree of attention problems that the individual with FASD has, they may need to be in an environment that is not distracting, that is not busy or overstimulating.

Now here's an interesting one—I don't know whether it's appropriate to have interaction with the committee. Is that appropriate, Madam Chair? Okay. Payment should be on a weekly basis. This was told to me by an adult with FASD. I invite you to suggest why that should be, just to wake you up—and I realize this is the end and I fully understand what you've been through.

The Chair (Mrs. Laura Albanese): You're saying payment should be on a weekly basis?

Mr. Barry Stanley: On a weekly basis, and I might add, I didn't get it straight myself. He had to explain it to me. So if you don't get it, don't feel too bad. Any suggestions?

Ms. Mitzie Hunter: I think if it's anything longer, it might be forgotten, it might be—

Mr. Barry Stanley: Well done. I am so impressed. You did better than I did. I'm very impressed; I'm very encouraged.

He said to me, "Look, I can get out of bed when it's next Friday that I get my money, but way down the road—what's a month?" Time is very difficult for him.

In simple terms, they get distracted. It's, in fact, a much more complex thing than that, but persisting with an aim and a goal is very hard. They live in the moment. So to get up every day for a month is tough. They'll get distracted, they'll sleep in and they'll lose their job and many other things. Well done, I say; I'm very impressed.

Ms. Mitzie Hunter: To be fair, I worked at Goodwill Industries for seven years, so I have a little bit of knowledge.

Mr. Barry Stanley: Okay, very good.

The employer and supervisors need to be very precise with instructions—there's so much we could discuss, but we don't have the time—and they may be best given visually rather than verbally.

In terms of further education, some of those with FASD can certainly go to further education, college and so on. Many who do, do not complete it, in my experience, but there are no statistics. It has not been looked into; it needs to be looked into. Those that do complete—I have seen that, as well—unfortunately, they often cannot apply their education that they've gotten to a job, and a consistent job.

Moving on to the next issue that you raised: the need for a range of available and affordable housing options for youth and adults. Many of the homeless have FASD. Because of their adaptive and executive disabilities, those with FASD lead chaotic lives and are often in conflict with others. This results in them moving to the streets.

There is a great need for accommodation that is supervised with an understanding of FASD. In my experience, group homes are not the best because of the likelihood of conflict, and I should add, unfortunately—hopefully it's changing—the lack of understanding and the rigidity to, what I would call, old-fashioned programs creates great difficulties for those with FASD who end up in group homes. The less the domestic facilities are shared, the less the conflict. So the environment needs to be adapted to the individual, not the individual to the environment. That is a consistent and persistent need throughout all of the situations we're talking about.

The need to provide social, recreational and inclusionary opportunities for children, youth and adults with FASD: Those with FASD feel different. It's very significant and not very much known, but actually very consistent. They feel different and they are often lonely. Their unaffected peers often reject them. Consequently, they tend to associate with the disaffected and disadvantaged, by whom they are easily misled and exploited.

Provisions for social, recreational and inclusionary activities and programs are important for the well-being of those with FASD. However, such situations are fraught with unexpected consequences, and even dangers. Consequently, supervision by those knowledgeable about FASD is advised, indeed is necessary. Non-affected peers in those situations need to be advised about the disabilities of the person so as to avoid misunderstandings.

The respite and support needs of families: Respite is desperately needed for the natural, adoptive and foster parents of children with FASD, yet it is so rarely provided. This results in divorce, failed adoptions and multiple placements, all of which, of course, are exactly what the child does not need.

A provincial respite program is required for FASD families. This should list the public and private respite services, their location, means of access and cost. The cost of respite can be a major deterrent, and government aid is needed in many cases.

For respite to be successful, it is imperative that the temporary caregiver understand FASD and be familiar with the child's needs, as indicated by the psychological assessments. If not, the child's behaviour will be aggravated on return to the home.

Policy on FASD has to include regular respite on a scheduled basis. In my experience, frequent short periods are more effective than infrequent longer periods.

The alternate caregiver should be the same person as often as possible.

The Chair (Mrs. Laura Albanese): You have just a little over a minute left.

Mr. Barry Stanley: Okay. So I'll finish with how government should most appropriately support those needs and provide those opportunities.

Future legislation should include provisions for an overall comprehensive policy on FASD that applies to all government ministries, departments and agencies. The IQ needs to be abandoned as a criterion for the provision of developmental services.

A full psychological assessment should be recognized as the intellectual profile of the individual that can and should be used by all departments and agencies throughout the life of the individual. Means should be provided for the individual's psychological assessment profile to be used by all government ministries, departments and agencies—education, justice, ODSP, housing, respite—throughout the life of the individual, so as to provide co-operative, comprehensive and continuous services, thereby significantly reducing the virtual cost of the assessments.

The committee's present definition of intellectual disability, which I will not go through, needs to be extended to include the psychological assessments required and the criteria as in the Canadian guidelines for the diagnosis.

FASD needs to be specifically recognized in any future legislation, since they will fulfill the requirements as in the above. It should be mandatory for all public employees who provide services to those with developmental-intellectual disabilities and the families that support them to have training in FASD and always refer to the psychological assessments of the individuals in order to understand the needs of the individual.

Thank you.

The Chair (Mrs. Laura Albanese): Well, thank you for your comprehensive and thorough presentation. I apologize that there is no time for any questions.

I want to thank you also for all the different articles that you've added to your presentation. I was just looking

at them, glancing at them, and they look very, very interesting, especially for the work of the committee.

Mr. Barry Stanley: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Hunter.

Ms. Mitzie Hunter: Madam Chair, I would like to ask the researcher to please pull the definition that was referred to on the guidelines for diagnosis of FASD because I think that would be interesting for us to think about, expanding our own definition to include it.

The Chair (Mrs. Laura Albanese): So thank you very much for presenting to us this afternoon.

MS. YVETTE FIALA

MS. BETTY MIDGLEY

The Chair (Mrs. Laura Albanese): We now welcome Yvette Fiala and Betty Midgley.

Ms. Betty Midgley: Yes. We're together.

Ms. Yvette Fiala: Good afternoon. I will take about 10 minutes, and my friend Betty, who was not originally on the list, will say a few words as well.

My name is Yvette Fiala, and I am a 50-year-old divorced mother of two boys living in Ajax, Ontario, in Durham region. My 18-year-old has autism, Tourette's and oppositional defiance disorder. My 14-year-old is perfectly healthy, normal—no problem. He helps me, actually, with the 18-year-old.

My biggest issue and concern is respite care for the immediate future and possible placement in a group home care for later.

1650

When my autistic son became an adult last year, I lost a lot of funding. On top of that, his behaviours became even more challenging. He has frequent meltdowns at home and in public, screaming profanities—that's the Tourette's—stomping his feet and spitting around. I find it extremely stressful; so does my younger son, who tries to help a lot. The screaming fits are so loud that even though we live in a detached house, even with closed windows, people walking on the street are stopping and wondering, "What is that?" My neighbour can hear it, and that's two detached houses, his and mine, with closed windows.

I actually brought a couple of short one-minute-in-length video clips I'd like to show you, because nobody can imagine what it really is like unless you live it in the moment.

Maybe I'll have to revive it; I'm sorry. It's frozen. I will just continue and it will come back on. I'm sorry. It was important to me. I spent some time filming it because I live with that every single day.

The Chair (Mrs. Laura Albanese): Can't make it work?

Ms. Yvette Fiala: It just froze, so I'm trying to start it up again.

Mr. Bas Balkissoon: Did you try F7? Sometimes it will unfreeze it. Then just restart the computer and it will probably kick in.

Ms. Yvette Fiala: Okay.

The Chair (Mrs. Laura Albanese): So maybe you could go on with the presentation and then we can come back to that.

Ms. Yvette Fiala: Yes, certainly. I often feel like a nurse at a psychiatric facility when I come home from work. It is harder and more exhausting than my day job. Respite care is important for me. I need it so that I can go occasionally on a mental vacation myself. But there is no respite available. I spent weeks and weeks last year contacting agencies in Durham region, only to find out that there is one adult respite home run by Community Living and quite a distance away. The wait-list is of 100 families-plus, and just a few spots available, if they're available.

There is private respite care; however, at a cost of \$22 to \$35 an hour. This is more than I make per hour when I work, so it is not really an option for me. I would be stressing about how I would save money for that kind of respite care.

Also, I'm afraid for the future. In two to three years, the boy is out of school, and then what? What to do with him? Even now when he's at school, it's a major struggle—like summer vacation: 10 weeks from late June to early September, when school is out. Just an example: The cost of two weeks at a residential summer camp is \$2,450. If I do that, that's two weeks out of 10 weeks I have to cover and I still have eight weeks to stress about how to find care for the boy during the day.

I tried to seek help from a specialist. I have seen two highly recommended psychiatrists in 2013. The last one told me, "Why is it that you came to see me, Mrs. Fiala? We psychiatrists cannot help because we simply don't know what is going on in the autistic mind. We just don't know." The doctor gave me a card with referral that I go and see a psychologist myself. I need counselling so as to come to terms with that that's how the boy is and he is not going to change.

For me, what would work the best is if there was maybe one spot at a group home that could be shared, something like: have the boy at a group home for three days weekly, then between me and my ex-husband we can do the remaining four days. Share one spot with somebody—for example, they can have four days; we have three days. I don't think such an option is available, and that would accommodate a lot of people, if they would like to share.

Right now, I am at a point where I feel like I need to give up the boy to the state. There have been moments in the past year where I really felt like I just have to drop him off somewhere at a hospital and tell them I can't handle it anymore. If I could get some reprieve, I'm still fine caring for the boy, because I love him, but not on a full-time, 24/7 basis. The toll that it's taking on me and my younger son is enormous. Just as an aside, last week, after one of those horrible screaming fits, my younger son actually looked up at me and said, "Mama, when are we going to get rid of him?" He was a bit sarcastic, but I knew exactly what he meant.

I have seen so many agencies, asking for help, and I have been turned away everywhere almost. I can tell you that it's extremely humiliating, because I feel like I am begging for services. Sometimes I don't even get a phone call back.

When I was thinking, let's say, of last year's—it was hotly debated in the media—cancelled contract to build some gas plant in Mississauga, I think, and the penalty cost of \$300 million, up to \$1 billion—when I think of how many group homes or respite homes could be built with that money, I would immediately put that in place.

Also, there is one agency called Family Alliance, I think. They really are against big institutions. But I was thinking of something in a format like a nursing home, an old age home: a bigger building where everyone's happy, where there is staff, there are recreational activities, but there are not old people living there, but maybe people with developmental disabilities. It doesn't have to be just small group homes, small place settings. I can say I was very happy with the Community Living children's respite house that was available in Whitby last year, but ever since he was cut after turning 18, I have had no respite whatsoever and it's just been brutal.

I am very disappointed because I wanted you to see something that I live with every day. I have it on a USB stick, but this thing just froze on me. It worked all the time before; I tested it. I would like to leave this as an exhibit. Please, if you can have a look at even one of those video clips, it's ear-piercing screaming. The boy is hitting his head like that. He's damaging furniture. He looks like he's hurting very much inside. I did seek help from psychiatrists, and they just don't know.

It's extremely embarrassing to even go with him in public. It can just come out of nowhere. A dog barking can set him off, or a little baby screaming, and he starts stomping his feet, screaming, "You fucking bitch, I'm going to fucking kill you!" at the top of his lungs, just like that. I can tell you, after each of those fits, it's like a piece of my soul is ripped right out from inside me, because it's extremely taxing on me.

Thank you very much for listening. If you could please watch at your convenience what I tried to put on the USB stick. Thank you.

Ms. Betty Midgley: I know it's the end of the day, so I won't take long, but I'm very excited about being here. We're very thrilled that this committee has been struck, because it has been a long time coming, but it's not easy for the two of us to even do something like this. We have to make arrangements for our sons; they can't be left alone. Bringing them would have been difficult, but leaving them at home is also difficult. We either have to hire a worker or we have to phone in sick or whatever.

1700

Anyway, I sent each of you an email earlier today, and it's essentially this seven-page document. I hope everybody reads it because it's filled with great suggestions and ideas. We have major challenges in our lives that most people don't have, so it's a little illumination on what we go through. But also, it's not just complain-

ing; there are a lot of really excellent suggestions and ways to get to our suggestions.

So, yes, that was the main thing. It's mainly about the crisis with adults with special needs—like, where are our sons going to live? That's the big thing. Long-term care, day programs, respite and then—I have 12 suggestions which I won't even get into here. I just really, really urge you all to read your emails today, because otherwise I'm just going to be reading this out, and it's the end of the day. I've even got ideas on how to raise funds and all that. You'll love it; you just will. You'll be totally into it, and you're my heroes for putting this together, so thank you. That's the main thing. I just really wanted to thank you guys for putting this together.

The Chair (Mrs. Laura Albanese): I want to thank you both for coming here today, for presenting to the committee.

Ms. Fiala, I'm so sorry—

Ms. Yvette Fiala: Can I—I just remembered. Just one minute or less. I remember there was a report issued called Ending the Wait. I was reading through it, and it just put me into deeper depression. If they say "ending the wait," when it's, in fact—in year one, we will target those whose parents are 75 or 80 and longer. Year number two will be parents maybe five years younger, and year number three will be parents 70 and plus. So the whole title "Ending the Wait" is almost ironic. It's not really ending the wait, especially for me, who is too young. But at the same time, I am exhausted, and I am just shaking sometimes, with my son at home with no services available at all. Thank you.

The Chair (Mrs. Laura Albanese): I'm so sorry for what you're going through.

I will allow for any questions that you may have, or any comments you would like to make. I know it's the end of the day and we all want to go, but I will allow that. Ms. Elliott?

Mrs. Christine Elliott: Thank you very much. Thank you both for being here today. Betty, it's great to actually meet you in person. We've corresponded so much, so thank you very much. I look forward to reading your recommendations with great interest. We want to work together with parents and families to make sure we can come up with some good suggestions.

Ms. Fiala, I can't even tell you how sorry I am for all that you're going through. I would like to talk to you as a fellow Durham region resident with some suggestions I have offline, so perhaps if you could stay a little bit later.

Ms. Yvette Fiala: I have emailed Joe Dickson, and even you, I think, and he sends me—they are very nice. They have their staff do research, and they send me what I already have and who I have already contacted. So it's not really good, but they are trying. But I have contacted every single of those let's say seven agencies, and everywhere they say, "No, sorry." And if yes, for respite, "It's for who is 75 years old, not you. You are too young." Thank you.

Mrs. Christine Elliott: Perhaps we can chat afterwards. Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo?

Ms. Cheri DiNovo: Yes. I just want to thank you and again express just our deep concern for you and your health and for your children, obviously. This is an untenable situation. The systems that are set up in the government currently are what are producing it. We've struck this committee to try to deal with that, to try to change that. That's the important part. Again, thank you for coming forward—

Ms. Yvette Fiala: If you can change anything—

Ms. Cheri DiNovo: Yes, well, that's what we hope to do: that we're not bringing you here for no reason.

I'm particularly interested when you were talking about Ending the Wait, because they were also here and presented to us. I don't think they even understood what that sounds like to you.

Ms. Yvette Fiala: Yes. It sounds like a joke.

Ms. Cheri DiNovo: What it sounds like to you is, "I'm going to have to wait 20 years to get some help." That's unacceptable. Thank you.

Ms. Yvette Fiala: Because I was at a point three times in the last year—this close to driving him somewhere, to emergency, and just telling them, "I can't handle him anymore. Just have him, please." I can't go through another tantrum. I can't go through any more of him yelling at me, "You fucking bitch; I'm going to kill you," and whatnot. There is a limit to what I can do.

Ms. Cheri DiNovo: Of course.

Ms. Yvette Fiala: Thank you so much.

Miss Monique Taylor: How are there not respite dollars for this family? It's unbelievable that there are no dollars to help this family for respite. There has to be emergency funding money. How is this family supposed to deal with this? I don't get it.

Ms. Cheri DiNovo: It's ridiculous.

Ms. Betty Midgley: Even when there's money available, that's not always the answer. There has to be a system in place for us. We are at the end of our ropes on many, many days. I'm just excited to be here, so I'm a little up, but it is very stressful. But it's not always a money situation either.

Ms. Yvette Fiala: I did contact Durham Mental Health Services. I work in a courthouse, and they have a mental health office. I was at my wits' end, so I went there. They put me in contact with somebody, and I got \$500 for emergency respite. That put me through the month of October, I think. I was hearing of something—but it ends, and then you have to think of what is next.

I am working with Community Living on something called DSNAP. I need to de-snap from my moment when I am close to a nervous breakdown. I think something will come out of that. However, they stress that I have to have a solution to my problem, because if they give me something, it's going to end again. In two months, it's going to end. And I don't have anything, because I just don't know what to have—something like a day off, or a week, a couple of days a month, and, yes, I can just tune out my stresses and whatever.

It's nothing compared to what I am saying here. If you watch the video clips—and he is like that sometimes at school—it's like watching a horror movie. I can tell you, I get sick to my stomach. My younger son often says, after he has a fit in public, "Mom, I have to go home. I have a tummy ache," because he is embarrassed. He loves his brother, but it's super difficult.

Thank you so much. I think it was Christine Elliott who put this together—at least, so Betty tells me. We work together, and we spend our lunch breaks talking and brainstorming about services for our kids. That's all we talk about, eh?

Ms. Betty Midgley: That's all we talk about, yes.

The Chair (Mrs. Laura Albanese): Before you go, I want to give the opportunity also to Mitzie Hunter to say something.

Ms. Mitzie Hunter: Betty and Yvette, thank you for being here, for being so open and transparent with your story, because it is hearing from the families and individuals that is really most impressive upon us, as a non-partisan committee that has come together. We recognize that the system needs to be fixed, and I think that's what you pointed out, Betty, that it needs to be a system-wide approach, a cross-ministry approach.

I see here in your story that there is a role for health, and perhaps even more specialized and intensive health interventions than what is readily available. We also know that families need respite solutions and programs that are there for them on a consistent basis.

This is just really to let you know that that's why we're set up. Our next task is to draft the report and to begin to look at recommendations.

Ms. Betty Midgley: That's good, because it doesn't just affect the child; it's the whole family.

Ms. Mitzie Hunter: That's right.

Ms. Betty Midgley: My daughter has anxiety. I have high blood pressure. My husband had a mini-stroke. My son is wonderfully, blissfully unaware of all of that, and in a way, that's great. We are always worried about him, every single day. We cannot just dash over here to Toronto without moving heaven and earth to make arrangements. We have jobs and we have other kids, and it's just a major undertaking. I think that people just are not aware.

The Chair (Mrs. Laura Albanese): I want to thank you once again for taking the time and arranging your life so that you could come here and present to us.

Ms. Betty Midgley: Thank you.

Ms. Yvette Fiala: Thank you.

The Chair (Mrs. Laura Albanese): Is there any further committee business? Ms. Jones.

Ms. Sylvia Jones: Just briefly, Chair. I think it was Cindy Mitchell who made reference to the need for 35 copies, and she's not the first presenter who has made reference to it. Is that a rule, or can we suggest to people that they can bring 15 and we'll figure it out?

The Chair (Mrs. Laura Albanese): They can also just send an email. I think we should be able to take care of the printing, just for the committee members—

Ms. Sylvia Jones: Maybe we need to reinforce that so that any further presenters who appear understand that there isn't an obligation to bring 35 copies of their presentation.

The Chair (Mrs. Laura Albanese): Good observation.

Thank you, and we are adjourned until February 19, 2014.

The committee adjourned at 1711.

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CONTENTS

Tuesday 21 January 2014

Developmental Services Strategy	DS-495
Families for a Secure Future	DS-495
Ms. Judith McGill	
Ms. Maureen Emmons	
Adult Protective Service Association of Ontario	DS-498
Ms. Dasha Choitova	
Woodview Mental Health and Autism Services	DS-501
Ms. Cindy I'Anson	
Ms. Robin Brennan	
Opportunities Mississauga for 21 plus	DS-503
Mr. Ross MacHattie	
Mr. Ronald Pruessen	
Toronto Developmental Services Alliance.....	DS-507
Mr. Robert Morassutti	
Mr. Colin Hamilton	
Faith and Culture Inclusion Network.....	DS-510
Mr. Paul Burston	
Mr. Harold Brennan; Ms. Debbie Brennan.....	DS-513
Ms. Rosanne Renzetti.....	DS-516
Fetal Alcohol Spectrum Disorder Ontario Network of Expertise	DS-520
Ms. Sharron Richards	
Ms. Nancy Hall	
Ms. Franke James.....	DS-522
Mr. William James	
Mr. Mitchell Feinman	DS-526
Canadian Association of Muslims with Disabilities	DS-528
Ms. Rabia Khedr	
Ms. Angela Bach.....	DS-532
Inclusion Initiatives Corp.....	DS-534
Mr. Don Hill	
Ms. Christina Buczek	DS-536
Ms. Cindy Mitchell	DS-539
Ontario Association of Children's Rehabilitation Services.....	DS-542
Ms. Siu Mee Cheng	
Ms. Louise Paul	
Justice for Children and Youth.....	DS-545
Ms. Mary Birdsell	
Ms. Samira Ahmed	
ARCH Disability Law Centre	DS-548
Ms. Kerri Joffe	
Ms. Maija-lisa Robinson	
Ms. Tebasum Durrani	
Mr. Barry Stanley.....	DS-551
Ms. Yvette Fiala; Ms. Betty Midgley.....	DS-554



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Second Session, 40th Parliament

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Deuxième session, 40^e législature

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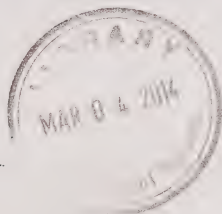
Mercredi 19 février 2014

Select Committee on Developmental Services

Developmental services strategy

Comité spécial sur les services aux personnes ayant une déficience intellectuelle

Stratégie de services
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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**SELECT COMMITTEE ON
DEVELOPMENTAL SERVICES****COMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE**

Wednesday 19 February 2014

Mercredi 19 février 2014

*The committee met at 1604 in committee room 1.***DEVELOPMENTAL SERVICES STRATEGY**

The Chair (Mrs. Laura Albanese): Good afternoon, everyone. It's great to see the committee reconvening. Today, we're meeting primarily to consider report writing, but before we do that, there are a number of items that I would like to bring to the committee's attention.

I would actually like to start, before doing that, with thanking our research department for all of the work that they have done, and for delivering the draft interim report. I think that all the committee members feel the same, so thank you. You did the work in a very short time, and it's done very well. Thank you so much.

To deal with some of the items that could be considered sort of cleanup for the committee, could I ask if we have consent to go into closed session? Is that agreed? Yes, Ms. DiNovo?

Ms. Cheri DiNovo: Yes, that's fine.

The Chair (Mrs. Laura Albanese): Just agreeing?

Ms. Cheri DiNovo: That's fine.

The Chair (Mrs. Laura Albanese): Okay. Thank you. For the remainder of the meeting, or just for a few minutes?

Miss Monique Taylor: You called it. What do you need?

The Chair (Mrs. Laura Albanese): We'll go into closed session, and then the committee may reconsider later on. Thank you.

The committee continued in closed session at 1606.

CONTENTS

Wednesday 19 February 2014

Developmental services strategyDS-559

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

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DS-17

DS-17

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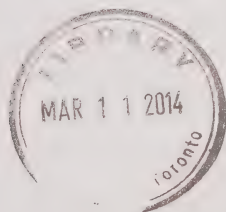
Mercredi 26 février 2014

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SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Wednesday 26 February 2014

Mercredi 26 février 2014

*The committee met at 1622 in committee room 1.*DEVELOPMENTAL SERVICES STRATEGY
DSO PROVINCIAL NETWORK

The Chair (Mrs. Laura Albanese): Good afternoon, everyone. We are in session. We have the provincial DSO network that is going to present to us, so I would ask you to come forward and to please take your seat. I want to remind members that this will be a presentation of up to 10 minutes. Then we will have 30 minutes for questions, divided equally by the three parties, so that's 10 minutes each. You may begin any time. Please start with your name and with your title for the purposes of our Hansard. Thank you and welcome to our committee.

Ms. Lea Pollard: Thank you very kindly. My name is Lea Pollard and I'm the chair of the DSO Provincial Network. I'm also the executive director of Contact Hamilton and we administer the DSO for the Hamilton-Niagara region. I'm joined today by some of my DSO colleagues who are sitting behind me.

I want to begin our presentation today by thanking you for the opportunity to come and speak before you, and also to thank you for the important work on behalf of Ontarians with developmental disabilities and their families, and your goal of improving their experiences and their outcomes with the adult developmental services sector. As a DSO network, we wish to be supportive and helpful to you in this process.

I would like to acknowledge that we did develop a written submission that I believe you folks have, which is fantastic. I won't go into the recommendations or the system challenges, as they are contained in the report, although I'd be very happy to answer any questions you may have around that.

In the slide deck that I have distributed, the systems issues are again captured on slides 15 and 17, and the DSO network's recommendations to help make some adjustments to our system are found on slides 19 through 21.

What I would like to do today, given the time that we have, is really to focus on the DSOs and what they do and their history. Starting on slide 4, I would like to speak a little bit about our DSO network and to just share that our network is a relatively new network. It was established in 2012. DSO organizations were implemented

in 2011. Our network is made up of nine organizational members, which include all nine DSOs from across the province.

Our primary objectives as a network are to identify and respond to relevant issues that impact DSO organizations, and also to support and promote provincial consistency, while at the same time needing to be mindful and respectful of local and regional uniqueness, and trying to balance the need to be responsive to our local and regional communities and to be provincially consistent in key areas.

Our goal is to develop a strategic work plan to guide our work activities over the next few years and then to develop that in response to emerging needs and trends.

For me to be able to speak about DSOs and what it is that we do and what we're responsible for, it's important for me to spend a minute or two talking about our roots. The roots of DSO organizations stem from the developmental services transformation that began in the adult developmental services sector in the mid-2000s. In large part, it was the ministry's response to concerns that they were hearing from families, from individuals and from service providers and their associations regarding the system and how it needed to improve. Areas that they addressed included access, service quality and transparency. The need for choice about the services that folks wanted to receive and how they wanted those services delivered were key areas of feedback.

In 2008, the ministry introduced new legislation to help guide a transformed system of adult developmental services for folks who were searching for services from our ministry, and that new legislation, in short form, is referred to as SIPDDA, the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act. Embedded in that act are key system elements of a transformed system. What's important to recognize and remember is that these key system elements have to be thought of as interdependent, as connected to one another; that these elements don't stand alone; and that for us to really achieve a fully transformed adult developmental services sector, all of the elements need to be implemented. They need to be mature, and we need to work together with all of the elements in an integrated way to really achieve the full benefits of them.

Slide 6 speaks to the key elements that are found within the legislation, and you will notice that one of the key elements in the legislation is the creation of application entities now known as Developmental Services Ontario organizations. While we have many responsibilities, at its core, the responsibility for DSO organizations is the fair and equitable and provincially consistent application process.

Other key elements of the system, when it's fully transformed, include: one provincial definition for eligibility—and we have that; that has been fully implemented—and the creation of a minimum set of quality service standards for service organizations as well as for the DSOs, and that has been implemented. We see in the legislation a confirmed list of services and supports that will be funded through the ministry.

Direct funding is introduced as a new component in the legislation that will enable folks to directly control how they would like their supports delivered when that option becomes available to them. We see direct funding partially implemented with the Passport Program, but we understand that that component will be enhanced over the years.

An element of transformation that has not yet been implemented—and, quite frankly, there are a lot of questions around what it is and when it's going to happen and what its role is—is called funding entities. So we really don't have a whole lot of context about that piece, but that is an element of transformation that has yet to be implemented.

I would like to draw your attention to slide number 7, which tries to bring together some of the complexity facing DSO organizations in terms of the different contexts in which DSO organizations operate. DSOs provide direct service to folks in the form of confirming eligibility, helping folks apply for adult developmental services and supports, and helping people link with the services they require. So there is a direct connection to individuals.

1630

But DSOs also have functions as it relates to helping the system. When we speak about the system, what's important to understand is that DSOs operate within three types of contexts:

The first is a provincial context. There are functions that we have that are embedded right in the legislation. Our policy directives tell us, "You must do this, and you must do it this way," for example, the application process or the eligibility confirmation process. The goal there is no matter where you live in the province, your experience with those key processes should be similar and consistent.

But DSO organizations are also responsible for specific regions within the province, and those regions differ between them. We are also responsible within our region for unique local communities. So balancing the need of ensuring that we consider the needs of local communities, that we consider the unique needs of our regions, with making sure we understand where we must be prov-

incially consistent and how we can be flexible to respond to local unique needs is certainly a task for DSOs to manage.

Slide 8 is a list of the mandates that DSO organizations operate within. That was part of the submission and so I'm sure that you've read that, and if you have any questions, I'd be very happy to answer them as much as I can.

With respect to slide 9, this is a visual representation, at a very high level, of some of the key processes DSO organizations engage in. What I want to draw to your attention here is that access to services is not a one-time event. It is in fact engaged in as many times as it's required or needed by families. So when an individual's needs change, that may trigger a time to call the DSO and update information about the person's needs, and then that would trigger us updating our service recommendations and actions on behalf of a family. Sometimes a person's situation changes and that also requires updating of their information.

What's important to note here as well is that once a person is registered with the DSO and their needs change and they have new requests for information or for services, they re-engage with the DSO at the point of updating their information. They don't have to redo the entire eligibility process.

On slide 12, I wanted to highlight on behalf of our network the key successes of DSO organizations. Each individual DSO organization can certainly point to very concrete successes and achievements in their regions. What we've done here is highlight at the highest level, at a provincial level, some key successes.

Really, for the first time in the province of Ontario we now have one visible, fair and equitable access process to the adult developmental services sector. We have nine single points of entry across the province. We have consistent eligibility criteria that used to replace individual eligibility criteria across the province. Our assessor staff have to meet not only some minimum standards for eligibility to be an assessor, but also must be certified and recertified on a regular basis. Of course, DSO organizations must maintain and adhere to quality assurance measures. I'll note that last fiscal year our DSO organizations underwent a compliance review and we were all successful in our compliance review.

An area of success that really, today, is actually a significant area of challenge, but it poses the opportunity to be a great area of success, is with the provincial database. We are experiencing a lot of difficulty with that because it's not fully operational yet, but it poses the greatest opportunity for us because we can have one database where every individual's needs are identified, where we can understand who is needing what service, what level of support they require in order to be well supported and have their needs met, and where the greatest needs in our community are. It will support not only understanding at an individual level what the needs are, but will also support really good, accurate, solid planning at the local level, at the regional level and also at the

provincial level, and it will be an unduplicated count. We don't have that yet, and that has been one of the biggest criticisms for DSOs. However, it poses the greatest opportunity for us.

DSOs have experienced challenges over the past two years and a bit, since we have been in operation. One of our key challenges has been that some key policies or procedures that relate to some of our key functions have not yet been given to us—so some key procedures around service vacancy matching or helping people access services across multiple regions at the same time: Those are directives we don't yet have. So what ends up happening is that DSO organizations, in order to be responsive to folks at the time that their needs are presented, are having to manage that on a one-off basis, if you will, where we try to work with one another to develop some interim processes. That can't always be accommodated because of the time pressures sometimes associated with individual needs, and that results in us not being as consistent provincially in some key areas as we should be.

A key challenge for us—and I've already mentioned it—is the fact that our provincial database is not yet fully operational. It's not very user-friendly, and when it came to us on our opening day, it did not come with orientation and training at that time. We've had to work with our province closely in helping to develop the database and use it to the best of our ability.

The database also, at this point in time, does not support all of the key business requirements or business functions of DSOs, which means that many DSOs have to use secondary or supplementary databases in order to capture business processes or capture key data, in order to be able to provide our communities with some level of information. DSOs have experienced higher-than-anticipated volumes than when we were planning for DSOs, before we became operational.

DSO agencies have had to deal with their fair share of criticisms. What I will tell you is that we understand that a lot of that has to do with changed management, introducing changes and experiences people have had. We look at opportunities like today and other opportunities within each of our communities to provide education around who we are and what it is that we do.

What concerns us as a network is that for some families, this is impacting their desire to be connected with the system to apply for services. Some families are feeling apprehensive, anxious or distrustful of the access process or the service system in general. I know that none of us wants that. We all want to be able to move forward and work in a supportive way with our families and individuals.

In terms of key challenges, I'll end with how our experience has been that the changed management, the need for information and context and education around developmental services transformation, around the introduction of DSOs, has not been at its best. We are looking to our ministry to provide leadership and guidance there to support us, as this is a very significant piece in the development of our sector. Again, the DSOs are one of several elements of a transformed system.

The Chair (Mrs. Laura Albanese): I'm going to stop you there. We had talked about a 10-minute presentation; we're now at 17, I think, although we haven't addressed the rest of the presentation. I don't know what the committee members want to do. I am just mindful of the fact that we'll have a vote later on. Unless you want her to continue, we could just move on to the questions. We have this with ourselves and we can read it.

1640

Ms. Lea Pollard: I am finished the presentation.

The Chair (Mrs. Laura Albanese): Oh, okay. Good.

Ms. Lea Pollard: So I was going to conclude on that and thank you again for your interest.

The Chair (Mrs. Laura Albanese): Thank you for being here and for giving us this overview and your point of view, which was needed by the committee. Ms. Jones, you may begin.

Ms. Sylvia Jones: Thank you, Ms. Pollard, for appearing. As the Chair alluded, we're glad that you have appeared because, as you can imagine, the DSO and the process of the DSO has come up a lot in our presentations.

I'm wondering if you know, as the network, what the annual budget is of the combined nine DSOs in Ontario.

Ms. Lea Pollard: I don't today, but that is certainly information that I can bring forward.

Ms. Sylvia Jones: Thank you. You made reference to when the provincial database will be fully operational. Have you any indication or can you share with the committee when you anticipate that would be? Because that follows up on—many of the questions that we end up asking research and other ministries are, "Where are the numbers?"

Ms. Lea Pollard: Thank you for that question. We don't have control over the development of the provincial database. We certainly, as a network, have been advocating routinely and passionately with the ministry to resolve the issues with the database and to ask as well for time frames around when that will be accomplished. We realize that part of the dissatisfaction with our service provider partners, in large part, is that we can't give them the fulsome information that they need to be able to do the kind of service planning that, as communities and regions in the province, we need to do.

I can tell you that we continuously advocate; I know that other provincial bodies have been advocating to the ministry. But I don't have a time frame for you. I wish I did.

Ms. Sylvia Jones: Yes, I wish you did too. You made reference to one of the reasons that the database is important, which is the assurance that we won't have shopping, for lack of a better word, for services, depending on which part of the province you're in. Quite frankly, I haven't heard that. We have nine DSOs. I don't hear, anecdotally, a lot of families saying, "I'm going to apply in this DSO and this DSO and see which one gives me better services." They're just too far from their home communities. Do you have examples of that happening?

Ms. Lea Pollard: I apologize if I gave that impression. I think what I was trying to say was that there

certainly are families who are prepared to look across regions for services. Some families feel the desperation of their situations. Others may have family members who live in different regions, and so having their family member supported outside of the region they currently live in would be okay, because they would be living closer to another family member. We certainly have situations where families wish to explore services from different regions. They would apply through the DSO in their home community, and the DSO then would share information with the other regions.

Ms. Sylvia Jones: Okay, thank you. I'll let my colleague go.

Mrs. Christine Elliott: I'd also like to thank you, Ms. Pollard, for appearing before the committee today. I just have a few questions. One is, we've heard from some of the families who have come to see us that they feel, in situations where the DSOs are also service providers, that if they're looking for more individualized programming and planning, they don't necessarily get offered that and they are really steered more in the direction of the services that are provided directly by the DSO. Are you aware of that as an issue? Has that been voiced to you?

Ms. Lea Pollard: That has not been voiced to me. My DSO in the Hamilton-Niagara region is not a provider of other adult developmental services, so we don't have that.

What I would recommend in situations like that is that the family connect with the DSO—the feedback process or the complaints mechanism—to identify their concern. Because if that's the case, then that needs to be addressed by the DSO.

Mrs. Christine Elliott: I think part of the problem is the families feel that they don't really have any alternative and they don't have an option to request anything else. They feel that you either accept what's offered, or nothing, and they're desperate and they'll take anything. I think that is something that we need to examine, I guess, in the course of this committee and the recommendations that we're going to make. I recognize that yours is not directly impacted, but it is something that we have heard about from families.

The other question I wanted to ask you is about the value of upfront planning with families. That was something that certainly those of us who were involved in the 2008 hearings for Bill 77—as it then was—the importance of planning early on with the families to understand what their wishes were for their child, and to the extent that the young person was able to voice their own wishes, that they have the opportunity to do that.

Do you feel that with the way DSOs are presently set up, that there is that truly independent planning and facilitation that is available to families?

Ms. Lea Pollard: Independent planning or person-directed planning is one element of a transformed system, so it's embedded in the legislation in SIPDDA, and that occurs outside of the DSO process.

So the DSO process, without minimizing it, is really about application to ministry-funded services. It's about

advising people of other service opportunities available in their local community that are funded from other sources, for example, and also advising families of the option of person-directed planning.

I know that person-directed planning is now starting to become implemented within our sector, so that's relatively new. I know that there is a formation of a network that families can go to to access person-directed planning.

I think there's also the notion or the element of transitional-aged youth planning on behalf of young people who are 14 and over, in anticipation of them leaving the children's services system, and trying to engage families at that point in time to think about planning for adulthood.

Mrs. Christine Elliott: Do you think it would be helpful to allow the DSOs, or someone else, to facilitate the planning before the formal assessment is done in order to really understand what the issues are for that young person and what their supports truly should be before you then let them know what's available in the community, so that you can truly individualize the plan for them?

Ms. Lea Pollard: I think that's wonderful. Certainly that would be the intent as well of the transitional-aged youth planning protocol that's being implemented across the province, to get families and individuals to think about planning that's broader than services, to have really meaningful connections in the community. To do that work first is very helpful so that you know what it is that you want to ask for in terms of services and supports.

Mrs. Christine Elliott: We also know that—I'm sure you're aware—there have been many criticisms levelled at DSOs, but bottom line, it seems to me that you're doing the best you can with the resources you have, but the reality is, you have long wait-lists because there aren't the funds available to be able to serve all the people who have those needs.

I see in your slide deck that the demand far exceeded the supply, and that was a surprise to some extent, but I'm wondering, if there are all these children in the pipeline who were already receiving SSAH, why it was such a surprise that they would have continued to need Passport funding when they reached the age of 18.

Ms. Lea Pollard: The decision to discontinue Special Services at Home at age 18 was a ministry decision. That was not a decision made by the DSO obviously, and I believe that occurred in 2012.

The piece in there about demand exceeding supply is in relation to the service sector. So the needs folks have far outweigh the services that are available in order to address those needs. The volumes at the DSO are higher than what we had anticipated when we were developing our expressions of interest to become the DSO for each of our regions.

I know that DSOs are doing the best they can to ensure that people receive a timely access process—when they call us, that their application appointment occurs as quickly as possible. But you're correct, some DSOs have fairly lengthy waiting lists, and that is a relative term.

I think the other thing I would say there is that—I lost my train of thought actually. I'm sorry about that. If I remember it, I'll finish my thought—sorry.

Mrs. Christine Elliott: Okay. I have another question.

Ms. Lea Pollard: Okay.

1650

The Chair (Mrs. Laura Albanese): Last one.

Mrs. Christine Elliott: All right.

What do you think would be the most significant recommendation that this committee could make with respect to the operation of the DSO?

Ms. Lea Pollard: I think the most significant recommendation would be twofold, and that is that the DSO organizations are provided with the tools that they need to be able to fully realize their mandate and their function, the most important being the resolution of the provincial database issue. That is integral to the work that we do. It should incorporate all of our business processes and it should be user-friendly. If we could achieve efficiencies there, we would be able to respond more quickly as well.

Mrs. Christine Elliott: Thank you very much.

Ms. Lea Pollard: You're very welcome.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you, Ms. Pollard, for coming before us. Have you had a chance to read some of the testimony that we've heard from parents, especially as it relates to the DSO?

Ms. Lea Pollard: Yes.

Ms. Cheri DiNovo: Just to follow up on my colleague's point: I don't think we heard anything nice. What we heard was a lot of frustration from parents. A phrase sticks in my head: "less system, more service." Parents and families and recipients felt that you're kind of the middleman. All you did was assess endlessly, and then, at the end of the assessment, if there was some service, that would be great, but there was just another long waiting list at the end of the assessment. I understand you're not in charge of providing those services. We heard that. I guess my first question to you is: What would you say to those parents?

Ms. Lea Pollard: That's a very good question and a question that requires a lot of thought. As a parent myself, I appreciate that question, and I think I can speak on behalf of our network members, that we appreciate the experience our families have. It is a real frustration that services are not plentiful enough to be able to meet people's needs in a timely way.

I would remind us that the introduction of Developmental Services Ontario organizations are one of several elements of transformation, that the system isn't yet at full maturity, and so the expectations we have today need to be managed a wee bit. While it's difficult for families to understand, and I appreciate it, because as family members, we are concerned about our son, our daughter, our sister, our brother, today, and ideally people's needs should be met today, but our system hasn't matured yet to that, and so it will take some time.

I know that DSO organizations are doing their very best to advocate with our ministry about moving forward transformation and communicating that, because I think a significant piece is that transformation is occurring, but it's not occurring within a context. People don't understand that there's more to come according to our legislation, that the system should be changing, that the system should be more responsive once transformation is completed. That's not really well understood or appreciated, because the change management of that hasn't really occurred. So we really need to go back and provide that context, provide that reassurance, at the same time.

Ms. Cheri DiNovo: Thank you. The other question I had was: What parents seem to desperately want is what has been called a system navigator so that when a child—first of all, there's a whole issue, of course, just getting an assessment when children are young, but suffice to say that when the assessment is made when the child is very young, someone can set up a plan and work with that family, not just till they're 18 or after they're 18 but for their lives. I heard you say something to my colleague about the difference there, so I'm wondering: Can the DSOs be system navigators in that sense? Can they morph into that?

Ms. Lea Pollard: I think that there are opportunities, and again, why I would really go back to, "What is the most important recommendation?": It is to really give the DSO the tools it needs to be able to fulfill its mandate and to give us the clarity to be able to do some of the work that needs to be done.

We hear, too, the importance of system navigation. Folks need to be supported as they make transitions. Folks need to know where it is they're going. That's very critical, and I think the DSOs have a role to play in that. I would be interested to work with our other partners around who is best and how we best support families.

One of our recommendations speaks to the need to bring together various ministries and various sectors to look at ways that we can, in an integrated way, best support people, because people are people regardless of the abilities or disabilities they have. Folks should be able to take part in what our communities have to offer. Having a developmental disability should not disqualify you from receiving the same services and supports other family members and folks receive, but we need to do that in an integrated way. We need to understand what other sectors need to know and how we can support that. What role can the DSO play in that? What role can service providers play in that?

Miss Monique Taylor: Thank you, Lea, for being here with us today. I have some questions designed around the application process that families go through. We heard several times that they're intrusive, that they're demeaning—these are words that I heard—they're unnecessary.

I'm seeing here that part of your mandate is that every five years that application process has to be completed. Is it the full extent of the application that has to be completed every five years?

Ms. Lea Pollard: We don't know the answer to that, and we would certainly advocate that it wouldn't be the whole kit and caboodle again, so we're looking for some direction around that.

Miss Monique Taylor: Yes, because that was a serious problem that I heard over and over again.

The qualification of the assessors—what exact qualifications do they have?

Ms. Lea Pollard: The qualifications of the assessor include having a minimum of at least five years' experience working in developmental services; having a post-secondary degree or diploma in a related field, ideally, developmental services; and having experience and knowledge. There's a policy directive specific to the assessor qualification, so you can get the detail right from the DSO policy directives.

In addition to that—that's just to get through the door and to be hired—assessors also have to undergo fairly significant training to be certified to administer the application package that we have today, and then they have to be recertified every 18 months thereafter.

Miss Monique Taylor: Do you believe that the process of the application works as you've seen so far? I mean, when we hear of a 30-year-old man who is sitting with his mother and his mother is being asked if that man can take care of his bathroom abilities—do you know what I mean? That's the intrusive part. Do you think those questions are absolutely necessary, especially done every five years?

Ms. Lea Pollard: The application process is a standardized process and assessors are trained in how to ask questions and must ask the questions a certain way and must ask all of the questions. That's part and parcel of the application process, and assessors really don't have a whole lot of flexibility around that.

We also hear from family members that the application process was actually helpful to them because it permitted them time to think through some of the areas that were talked about. But different people have different expectations.

One of the things assessors do during the application process is give families a link to a confidential survey where families can provide detailed feedback about the application process itself and the tool. So we really encourage families to give us feedback around that, and not to us, but directly to the ministry.

Miss Monique Taylor: Thank you. Nine DSOs are set out across the province; they're the first point of contact. What happens if I'm 200 miles away from a DSO? How does that work in rural Ontario? Do you know?

Ms. Lea Pollard: I don't know the answer to that specifically. However, I would presume that the DSO would have processes in place, whether they travel to folks on a routine basis or not. But that would be a really good question. I can bring some information back to you around that if you are interested in that.

Miss Monique Taylor: Thank you.

Chair, to research, could we find an answer to—which question was I asking? You want to talk about brain breaks.

1700

The Chair (Mrs. Laura Albanese): The application, maybe?

Miss Monique Taylor: The application process.

Ms. Lea Pollard: Or the feedback?

Miss Monique Taylor: Yes, the feedback, thank you, and comments for the application process. If we can get information on that, maybe a breakdown of what it looks like, maybe some of the feedback answers to it. Would we be allowed to access those?

The Chair (Mrs. Laura Albanese): From the ministry. Okay. Thank you.

Miss Monique Taylor: Thanks, Lea.

The Chair (Mrs. Laura Albanese): We'll now move to the government side. MPP Hunter?

Ms. Mitzie Hunter: I will start, and Ms. Wong has questions, as well as Mr. Balkissoon. If I can say that what I heard in Thunder Bay when the DSO presented to us on that final day was that they had satellite offices as well to deal with the geography, but geography was a challenge. He did say that to us.

Thank you, Ms. Pollard. It was really comprehensive. I feel that you're speaking to us at a very unique point in the work that we've been tasked to do, which is to look at the developmental services supports that are provided to adults with developmental disabilities and dual diagnosis across the province, and how we integrate cross-ministry support across a lifetime.

I think that the vision that you have to look at an integrated way of support for people is very consistent with the mandate of this committee. We are at the mid-point, and the next stage, once the draft report is tabled, is to move into report-writing for recommendations. So I think that you're here at a pretty good point in the work that we've been tasked with.

I wondered what you have seen, with your years of experience in the field, in terms of what has changed, but more specifically, what you hope to see in terms of once this work is complete. How will it improve supports to people with developmental disabilities? Because that's what we're ultimately trying to do.

Ms. Lea Pollard: Thank you for that question. I'm going to start quite broadly with my answer to that because I really feel—and I'm speaking personally now—that what we need to do is to embrace folks who have developmental disabilities as citizens first, and that we need a real, integrated approach to supporting folks. We need to understand what folks need and we need to be able to provide the supports that they need in a way that is meaningful to them.

I would hate to see the creation of a parallel sector for folks with developmental disabilities. People are people, and they are citizens of this province, and if I happen to have a developmental disability and I have health needs, I should be able to get my health needs managed and supported through the health sector, through the education sector, through housing etc. The notion of coming together across ministries to work together, not just in a partnership way, not just in a collaborative way, but in a

really integrated way—what can the developmental services sector give you by way of information, knowledge exchange and support to be able to support our citizens with developmental disabilities? What are the specific supports that really can only be provided by the developmental services sector? And we should then be freed up to be able to provide those services and supports in a way that is timely and in a way that is individualized to that person.

My sense is that the only way to achieve that is by coming together in an integrated way. I think that our ministry has the opportunity to not only set the vision and to set the policy, but to bring our ministries together and to lead that, and to be the champion for that. And DSOs, service providers, families and other sectors at the decision-making level can come together to facilitate and implement that.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): Ms. Wong.

Ms. Soo Wong: Thank you very much for your presentation. I just want to get clarification. The current legislation covering DSO—does it prohibit the whole network from collaborating and communicating with sectors like health right now?

Ms. Lea Pollard: It certainly does not prohibit us from doing that at all. I think that at the individual DSO level, each of us is invested in each of our communities and working with other systems and sectors. Unfortunately—or fortunately, without passing judgment—we're so early on in our implementation as well. A lot of our focus has been on implementing our service, doing that the best that we can with the resources that we have available to us. We've been focused largely on that.

We have to prioritize issues as they come before us, and I think that we do that. We have struggled, as a network, to be able to come together on a consistent basis to work through provincial consistency issues. That has really been a function of workload and managing all of that, but the desire to do that is there.

Ms. Soo Wong: I'm particularly interested: Has your network invited the LHINs—because the local health integrated networks also have an association similar to your network. Has there been any crossover conversation? Because we consistently heard across the province that there needs to be some kind of collaboration, because your constituents, the clients, need not only the DSO support, but they definitely need a lot of health care support.

Ms. Lea Pollard: Absolutely.

Ms. Soo Wong: So at your provincial level at the network, have you reached out to go over and have some conversation with the LHINs on how to best service your clients and the families?

Ms. Lea Pollard: The short answer is no, we have not done that. Part of the work that we need to do as a network is that development of that strategic plan: What are our priorities? Who are the core groups of folks we need to be meeting with and working with closely?

Ms. Soo Wong: The other thing I consistently heard—my colleague Ms. DiNovo asked this question

earlier. We consistently heard across Ontario that families and clients are very, very hurt that the staff from DSO have been disrespectful, have been intimidating and, most importantly, have not heard. What service or support does the DSO network have, in terms of customer service? Because we consistently heard families and individuals saying the DSO has been intimidating, has been bullying. I asked the question at Thunder Bay to your colleague at DSO up there, and I did not get an adequate answer.

I want to know: Does your network address the issue of customer service? Because no government-funded agencies should be intimidating their clients. I need to know, from your network: Do you talk about customer service? Do you talk about making sure their concerns are being heard and that the families have been dealt with, not being disrespectful? Because this is not acceptable behaviour, what I'm hearing across Ontario. Does your network talk about these kind of concerns?

Ms. Lea Pollard: Thank you for that question. It disturbs me to hear that that has been the experience of families, and that concerns me. That should not be the experience of families. Every DSO has a complaints process and has a feedback mechanism, and we rely on hearing that feedback so that we can address that directly with the DSO that is involved. That's important.

As a network, we have not yet come together in a very focused way around the notion of customer service. That is one of many areas that our DSO network needs to examine. But I would certainly encourage families to go to their local DSO and find out what that complaints process is—that should be made available—as well as the feedback process, so that their concerns can be noted and then supported, because that should not be the experience of people when they come to us for help.

The Chair (Mrs. Laura Albanese): Mr. Balkissoon.

Mr. Bas Balkissoon: Thank you very much. I just want to understand your recommendation where it says, "MCSS to resolve all outstanding issues with the provincial database." Can you elaborate on what the issues are, what you need this database for and what is in the data itself?

Ms. Lea Pollard: Yes. The database contains the application package, so the information that people provide to us during the application process is contained in there. The database should also be able to support some of our key functions. So, for example, when there is a service vacancy available, that database should be able to help us, in a very timely way, identify who is waiting for a service like that and what their priority is, to help us with the matching and linking process. That's an example.

We need a database that we can generate reports from. Right now, we can't generate our own customized reports. The ministry has been able to provide us with some reports, but they're more generic in nature. We need the capacity to be able to run reports to say with confidence, "These are the number of folks who are waiting. This is kind of what their profile is. This is what they're waiting for."

Those are examples. Our database is also not at this point in time very user-friendly.

1710

Mr. Bas Balkissoon: Okay. Just to clarify: Is the data stored centrally?

Ms. Lea Pollard: Yes. We have one provincial database, and the data is stored in there, and each DSO has access to its data.

Mr. Bas Balkissoon: So you're basically saying the program itself doesn't have the features you're looking for.

Ms. Lea Pollard: It needs to be further developed, yes. That's right.

Mr. Bas Balkissoon: How long ago did you receive access to this program?

Ms. Lea Pollard: We received the database when we opened our doors on July 1, 2011.

Mr. Bas Balkissoon: And how long ago have you complained that these are the issues, that you need additional functionality in the program?

Ms. Lea Pollard: We have been quite open about our need to have that database meet our needs since the beginning.

Mr. Bas Balkissoon: So it's over two years.

Ms. Lea Pollard: Yes.

Mr. Bas Balkissoon: Do you know how much collaboration and consultation the ministry did with the user groups before they got somebody to write this program?

Ms. Lea Pollard: I believe the program is what's called an out-of-the-box program, so it was already developed. Now it needs to be customized to the work that we do, so that's part of the challenge.

Mr. Bas Balkissoon: Is it a program we bought from another province, or just bought off the shelf from a supplier?

Ms. Lea Pollard: Do you know what? I don't have all of the detail around that, and I know that the ministry would be the one that would be able to give you a really good, appropriate answer around that. I'm sorry; I don't have the detail.

Mr. Bas Balkissoon: Thank you. Now I understand your problems.

The Chair (Mrs. Laura Albanese): Thank you. The time that we had allocated to each party has expired, but I don't know if there are any other questions that the members want to ask. Yes, Ms. Jones?

Ms. Sylvia Jones: Not so much for our presenter, thank you, but we have heard reference to—I keep calling it Bill 77, because when I was in committee it was Bill 77, so whatever its formal name is now—that there were sections of that legislation that have not received royal assent. I think we've asked, but if we haven't, can we get those specific sections that have not yet received royal assent from 2008?

The Chair (Mrs. Laura Albanese): Royal assent. Okay. Therefore, I can release our presenter. Thank you very much for appearing before the committee.

Ms. Lea Pollard: Thank you. It's been a pleasure.

The Chair (Mrs. Laura Albanese): It's been very helpful to have you here, and we thank you all for the work you do every day. We know it's very important, especially for people and families with disabilities.

Ms. Lea Pollard: Thank you very kindly.

The Chair (Mrs. Laura Albanese): Thank you.

Ms. Mitzie Hunter: Excuse me, I—

The Chair (Mrs. Laura Albanese): I'd like to know at this point if there are any further directions for the researcher—

Ms. Mitzie Hunter: I do, yes.

The Chair (Mrs. Laura Albanese): —and that's what Ms. Hunter is about to ask. Please.

Ms. Mitzie Hunter: Thank you, Madam Chair. I thought you were going to move on to another area.

I really like Ms. Jones' question about what pieces of the legislation are still outstanding. I would also like to understand any known costs associated with its further implementation, if that was known.

The Chair (Mrs. Laura Albanese): Any further questions?

Ms. Erica Simmons: Costs?

The Chair (Mrs. Laura Albanese): Costs.

Ms. Erica Simmons: Costs associated with further—

Ms. Mitzie Hunter: Attached to the—yes.

The Chair (Mrs. Laura Albanese): With further implementation.

And then I would like to know—are we done with directions to the researcher? Never, eh?

Ms. Wong.

Ms. Soo Wong: Madam Chair, on our table this afternoon, there were a bunch of reports from the ministries, different ministries' responses. I think they were addressed to the researcher. I have some questions from these reports. I wanted some clarification. Is it a good time to ask them now, or do we wait until—

The Chair (Mrs. Laura Albanese): Sure, depending on the time.

Ms. Soo Wong: I just have two quick questions. Tab number 25 deals specifically, I believe, with my question dealing with the Healthy Homes Renovation Tax Credit. This is the first time—I don't know if maybe other members of the committee know about this program. At the bottom of page 2 of this memo, it talks about the Home and Vehicle Modifications Program. I don't know—I've never heard of—

The Chair (Mrs. Laura Albanese): Sorry; did you just say tab 25?

Ms. Soo Wong: Tab 25 is a response from the Ministry of Finance to my question on the Healthy Homes Renovation Tax Credit. This is the first time that I've ever heard of this Home and Vehicle Modifications Program. But the interesting piece is, if it has been around—I don't know how many years—remember, there were witnesses saying that we should expand our healthy homes tax credit from seniors to those who are developmentally or physically disabled, so they can get access to it, and yet the Ministry of Finance indicated this particular program. So, my question here, Madam Chair, is:

How much information is out there to promote this program to the public? What is being done? Because if this program has been around for many years—my colleagues Mr. Balkissoon and Ms. Jones say it has been here for many years—how come a witness, and I believe it was in London, expressed concern that we are focusing only on seniors and not support? If it's around for many years, where is the responsibility of this ministry to let it be known to DSO or elsewhere who the clients are who need these kinds of programs? Obviously, constituents didn't know about the program and are asking for the government to fund and support them. That's what I want to ask.

The Chair (Mrs. Laura Albanese): Mr. Balkissoon.

Mr. Bas Balkissoon: Madam Chair, the vehicle modification program is the program that you can modify your vehicle if you can't use your feet or your hand or whatever. They create other things. The home part of it is the ramps that you need for your home and other stuff.

I think what the deputants were asking us for is the new credit, which is the \$1,500 tax refund if you want to change a door handle or a bathtub or whatever. That is what they didn't have access to, and they wanted to get that program extended to give them access to those additional funds.

The vehicle fund has always been available, as I know, as part of ODSP and all the other things.

Ms. Soo Wong: It may not be, because my question here is: Are the constituents who are currently in ODSP aware of these programs? Are there similarly differences between the Healthy Homes Renovation Tax Credit versus the Home and Vehicle Modifications Program?

Mr. Bas Balkissoon: There's a huge difference.

Ms. Soo Wong: I don't know the differences. But it would be good to know.

The other piece here is, I wonder: Are the clients currently at the DSO aware of these programs? Because they shouldn't be coming to the committee if they knew about the program, and making that recommendation to the committee.

The Chair (Mrs. Laura Albanese): So, just to summarize: You would like the ministry to tell us how—

Ms. Soo Wong: The differences between the Healthy Homes Renovation Tax Credit—

The Chair (Mrs. Laura Albanese): The difference between the two programs—

Ms. Soo Wong: Yes.

The Chair (Mrs. Laura Albanese): —and then how they are promoting these programs—

Ms. Soo Wong: To the DSOs.

Mr. Bas Balkissoon: But I think we should clarify, Madam Chair. The folks who are coming here—the disabled person was a child or a family member. That person doesn't have access to the Healthy Homes Renovation Tax Credit. It's the homeowner who does. So, if I'm a disabled person and I'm a tenant, I don't have access. I think that's what they were complaining about.

Ms. Sylvia Jones: Or if you're a mom or a dad looking after an individual—

Mr. Bas Balkissoon: Yes, you don't have access. That's the problem. The Healthy Homes Renovation Tax Credit was a one-time deal for a specific time frame, and I believe the program has closed. Somebody mentioned to us, when we were in London—

The Chair (Mrs. Laura Albanese): I don't think it's closed.

Interjections.

Mr. Bas Balkissoon: Okay. When we were in London, I remember clearly the person saying, "I don't have access to this program because I'm not a homeowner; I'm a tenant. And the government should look at changing that to allow me to have access to it because I'm disabled."

The Chair (Mrs. Laura Albanese): It says here that the home renovation tax credit is only available to people who owe Ontario personal income tax, so that may be one issue.

Mr. Bas Balkissoon: I think the other issue would be they don't own their home.

The Chair (Mrs. Laura Albanese): People who qualify but have lower incomes would not claim this tax credit because it would not provide them with any tax savings. I guess not everybody qualifies, and that may be the issue. In any case, if we could ask for some clarity of the different programs.

Yes, Ms. Wong?

1720

Mr. Bas Balkissoon: I had one other request. I don't know how to deal with this—

The Chair (Mrs. Laura Albanese): Okay, so I'll go to Ms. Wong and then Mr. Balkissoon.

Mr. Bas Balkissoon: I don't know how we're going to deal with this, but I think we need to have a complete presentation on this database so we understand it. To me, the key functionality of DSOs is to have a working database that is networkable, that can tell them when things are available and provide service at a faster rate. It seems as though it's not there. Why was the program developed before consulting the users, and who did the ministry consult to build this thing? Or did they buy it off the shelf?

The Chair (Mrs. Laura Albanese): Should we ask for that?

Ms. Sylvia Jones: Yes.

The Chair (Mrs. Laura Albanese): A presentation on the database?

Ms. Sylvia Jones: Why can't we just get the details? I mean, bless them, but I don't want to spend a lot more time having the ministry come and do ministry speak, so let them give us the material on where the program came from and, quite frankly, why they don't have a database that the DSO can work with.

Mr. Bas Balkissoon: And why the program came after the legislation rather than before.

The Chair (Mrs. Laura Albanese): Okay. We'll request that information.

Ms. Sylvia Jones: But I don't want another presentation from the ministry.

Miss Monique Taylor: How are they maintained? Who's watching over those data banks?

The Chair (Mrs. Laura Albanese): Can we have a list of questions that the members could put together? Maybe everyone has their own list of questions that we want to send to the ministry.

Mr. Bas Balkissoon: I'm more concerned that if I put a question now and they give me an answer, I'll have another question, whereas if they're here—this could be very, very technical, but very, very important, because the DSOs will never be successful unless you have a proper, working resource tool in your program.

Ms. Sylvia Jones: You're really good at burning time, Bas.

Mr. Bas Balkissoon: Well, you'll never fix the problem if their basic tool to connect a client to a service is not there.

The Chair (Mrs. Laura Albanese): I'd like to hear Ms. DiNovo's opinion.

Ms. Cheri DiNovo: Can I just make a suggestion? I think we've heard the question; we would like a response from the ministry to her concerns. End of story. Let's give them a page or two. We've already got this much paper. I think a page or two in response to her concerns would be appropriate.

Ms. Erica Simmons: Key challenges or responses?

Ms. Cheri DiNovo: Key challenges. She focused on the database; let's have them focus on the database and give us a response.

The Chair (Mrs. Laura Albanese): I don't hear consensus for another presentation.

Ms. Wong and Ms. Taylor.

Ms. Erica Simmons: Can I just clarify? Just the database or key challenges, especially the database?

Ms. Cheri DiNovo: I think we're centring in on the database. I think I agree that if they don't have a database that works, what are they doing?

Miss Monique Taylor: Right. She also stated that she didn't know what the financial—

Ms. Erica Simmons: The total budget of all the DSOs?

Miss Monique Taylor: No, there was something else that was supposed to be part of the package—the mandate that they didn't receive.

Ms. Cheri DiNovo: Actually, that was a question that you had, Monique: What is the cost of administering DSOs, period? What is the cost?

The Chair (Mrs. Laura Albanese): Yes, the initial question.

Miss Monique Taylor: One of their things under the legislation—

Ms. Mitzie Hunter: Some \$27 million.

Miss Monique Taylor: —for the direct funding is the creation of funding entities that will eventually have a role with respect to funding. They have no idea what the funding entities are, or what that means. They've been trying to find out and they still don't know what it means, but it's supposed to be part of the broad picture.

The Chair (Mrs. Laura Albanese): So this one has not been implemented and they don't know much about it. It's not the application entities; it's the funding entities. Is that correct?

Okay. So, I had Ms. Wong still in queue.

Ms. Soo Wong: Madam Chair, tab number 23 was, again, put on the table for us to review, from the Ministry of Education. I believe it's also to my question about the membership of SEAC on page 5 of the report.

So I was correct: Parents are not excluded from becoming a member of SEAC. That's what it says right there. I think maybe we should put that somewhere in the report process, because there's a perception out there that parents with children in the system cannot be members of SEAC, and it's clearly written here. It says SEAC membership—

The Chair (Mrs. Laura Albanese): Yes, but it also says "however."

Ms. Soo Wong: Yes, but at the bottom here, it says, "I would encourage anyone considering becoming a member of SEAC to contact the local school board directly for more information." So parents are not exclusively—am I reading correctly?

Ms. Erica Simmons: We said that in the report. They're not excluded—

Interjections.

Ms. Erica Simmons: A parent can sit on the SEAC, but they must do it as a member—

Ms. Soo Wong: —of the association.

Miss Monique Taylor: So they're not there as a parent. They're there as—

Interjections.

The Chair (Mrs. Laura Albanese): A parent would need to be a member of a local provincial association and would need to be nominated by that local association for representation.

Ms. Soo Wong: I think this is something that we need to put in our hat when we think about the final report. That's what I was trying to say when I read that.

The Chair (Mrs. Laura Albanese): Maybe we want to change that regulation.

Any other hands up? Okay, Miss Taylor, Ms. Hunter and Ms. Jones.

Miss Monique Taylor: When we're also talking about the database, I want to know who does their IT of the database. So when they're having problems and issues with the database, and they need to move it forward, who are they speaking to and who is supposed to be doing that?

The Chair (Mrs. Laura Albanese): Okay. Ms. Hunter.

Ms. Mitzie Hunter: One of the things—I didn't ask the question of Lea, but it really struck me that the cross-ministry integration is not happening. I didn't hear them being aware of how to support the system and I am concerned about that. It just feels like it's not happening, and I'm not sure if this group is the right group to answer that question, but there seems to be an expectation on the part of families and individuals that they can go to this DSO and—

The Chair (Mrs. Laura Albanese): Find answers.

Ms. Mitzie Hunter: Right, and receive a certain service delivery. But the coordinating body for the act is not integrated into cross-ministries. It just seemed as if they were a world unto themselves.

Miss Monique Taylor: I didn't hear her response when you asked if she speaks with the LHINs.

Ms. Mitzie Hunter: No, she does not.

Interjections.

Ms. Soo Wong: Exactly. That's why I asked that question, because I just got the feeling, unless they've been directed by the legislation, they're not going to go reaching out. There was no intent, even though their clients do need their health care support badly—I mean, I didn't even bother going to deal with the CCAC, dealing with the long-term-care piece, but I got it very clear, they were working in isolation, in silos, and they were not even planning to talk to the Ministry of Education. Their clients are obviously over 21, but they're still working with those who are currently 17 to 21 so they can better transition to the real world.

The Ministry of Training, Colleges and Universities—they seem to be working in silos, in isolation. That's why I think part of the problem is that they just—I mean, they used the line that they have to “implement the mandate,” blah, blah, blah, but I don't see them reaching out to go over to support their client and their needs in terms of employment, in terms of training, colleges and universities, and particularly the health piece. I was struck—even though they're a newly created organization, a provincial organization, they seem to work in silos. That's what I'm sensing in that piece.

Interjection.

The Chair (Mrs. Laura Albanese): Sorry, I have to go one at a time for Hansard. Otherwise, they're having difficulty. Thank you, Ms. Wong. Next, Ms. Elliott, did you have a comment? Otherwise, I'll go to Ms. Jones, who was waiting from before.

Ms. Sylvia Jones: A separate topic: Did I hear \$27 million is the annual operating budget for all nine DSOs?

The Chair (Mrs. Laura Albanese): I'm sorry, \$27 million, or is it \$7 million? Ms. Hunter?

Ms. Mitzie Hunter: It's \$27 million.

The Chair (Mrs. Laura Albanese): It's \$27 million.

Ms. Sylvia Jones: Okay. The database that doesn't work and—we'll get that into the recommendations.

The Chair (Mrs. Laura Albanese): Ms. Elliott, did you have a comment?

Mrs. Christine Elliott: Sure. Just to respond to Ms. Wong, I agree with you that there should be much more integration, but I think we shouldn't necessarily be surprised that they haven't contacted the LHINs because they're responsible to Comsoc, and it's a different ministry. So I think they really don't have a mandate to do that. I think the mandate needs to come from above and probably not even through Comsoc. I think that's something that we need to wrestle with as we make our recommendations about the appropriate vehicle to bring all of these groups together from the various ministries, to look at this holistically. I think that'll probably be one of the biggest things that we'll have to deal with when we start our deliberations.

The Chair (Mrs. Laura Albanese): So, before we get called upstairs, I wanted to also ask the committee: What should we do next week? I understand that we had another organization that Mrs. Elliott had requested we speak to, but so far we have not been able to get in contact with them. If we do get in contact with them, we can certainly ask them to come and present. If we do not, should I call a meeting for next week? Do we want to start report writing?

Ms. Sylvia Jones: Yes.

The Chair (Mrs. Laura Albanese): Open or closed session?

Interjection.

The Chair (Mrs. Laura Albanese): Closed.

Ms. Sylvia Jones: That's standard.

The Chair (Mrs. Laura Albanese): Yes, that's usually standard.

Ms. Sylvia Jones: Yes. I think that while there are sections that we still want to learn more about, there are certainly some parts of the interim report that we can start pulling out and making suggestions on. That would make, I know, the researcher's job easier, if they could start that sooner rather than later.

The Chair (Mrs. Laura Albanese): Okay. So then we're all in agreement?

The Clerk of the Committee (Mr. Trevor Day): I was just going to say, if we can get the presenter, it will be open session to start with, with the presentation. If not, it'll be a closed-session meeting for report writing and discussion.

The Chair (Mrs. Laura Albanese): Okay. Thank you. We are adjourned.

The committee adjourned at 1731.

CONTENTS

Wednesday 26 February 2014

Developmental services strategy	DS-561
DSO Provincial Network	DS-561
Ms. Lea Pollard	

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON
DEVELOPMENTAL SERVICESCOMITÉ SPÉCIAL SUR LES
SERVICES AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Wednesday 5 March 2014

Mercredi 5 mars 2014

The committee met at 1616 in committee room 1.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): Good afternoon. The Select Committee on Developmental Services is now in session. I hope everyone saw that we presented the interim report this afternoon in the House.

Ms. Sylvia Jones: You did a fine job, Chair.

The Chair (Mrs. Laura Albanese): Thank you I appreciate it.

We have received a number of documents, and I guess we'll go over these afterwards.

MR. MARK WAFER

The Chair (Mrs. Laura Albanese): In the meantime, we do have a presenter that is here with us this afternoon: Mr. Mark Wafer. Good afternoon. How are you?

Mr. Mark Wafer: Oh, my goodness. [*Inaudible*] and I'm over there talking to everybody else.

The Chair (Mrs. Laura Albanese): Sure. Well, welcome to our committee. You will have up to 10 minutes for your presentation. Then that will be followed by 30 minutes of questioning, if the committee members wish to do so. It will be divided in 10 minutes for each party. You may begin anytime.

Mr. Mark Wafer: Okay. Well, thank you very much for having me here. First of all, I'm a Tim Hortons franchisee with seven stores in Scarborough. In the last almost 20 years I've hired almost 100 people with disabilities, and about 35% or almost 40% of those have been intellectual disabilities.

My expertise is in opening doors at the corporate and business level by explaining the many, many business benefits to being an inclusive employer. By using a business model and peer-to-peer discussions, I've had tremendous success in doing so. More than 1,000 people have found work through the discussions that I've had through one of our programs, which is known as Rotary at Work, but also from discussions with chambers of commerce and a number of other initiatives. When we discuss inclusive employment from a business-case model, we will open doors. That has been my expertise up to now.

The most important aspect of a person's life really is the fact that they have a job—a job that is meaningful and that is competitively paid. It's what we want for ourselves. It's what we dream of when we're growing up. It's what we expect for our children as well.

In Ontario today we have a 70% unemployment rate for people who have a disability. HRSDC says 50%, but if you take a look at the number of people who have dropped off the grid and people who have given up out of sheer frustration, we're looking at about 70%. With 1.9 million people in the province who have a disability, 70% of those is a huge number that's costing us, in ODSP support payments alone, about \$4 billion, and that's growing by 8% per year.

For every 100 people we take off of ODSP and put into the workplace in meaningful and competitively paid jobs and for those that we're taking off of benefits, and creating taxpayers, we're saving the economy about \$1 million.

There are many reasons why companies are not hiring them. There is a series of myths and misperceptions that they're buying into. There's a fear, a tremendous amount of fear, that the employee will be less productive, less safe, will take more time off, and be a human rights issue at the end of the day. None of that is true. They are all myths and misperceptions. The reality is that hiring people with disabilities in meaningful and competitively paid positions is good for business.

My employee turnover rate in my seven stores is 40% per year. The average for the industry and the average for Tim Hortons, McDonald's and the rest of the QSR in the Toronto region is 94.5%. For me to replace one person—the person who served you your coffee this morning—it's \$4,000. By the time we look into advertising, uniforms, training, procurement, interviewing and so on, it's about \$4,000. So if my turnover rate is 40% and my friend down the street is doing just as good a job as I am at 94%, the bottom line is I'm making more money—on the bottom line. That's really important.

The discussions that we have with our children today—when parents have a child who has a disability, we tend to look after them. We tend to smother them with love, and we let them know that as they grow up they're going to be looked after. But the siblings and the children who don't have a disability, we tell them to dream about what they want to be when they grow up.

Even if it's a dragon slayer or an astronaut, it doesn't matter; at least they have dreams. But the child who has a disability, we tell them they're going to be looked after. We have to change that mindset. Stakeholder groups and social service agencies are complicit in that mindset as well.

We don't even talk about the workplace until they're 17, 18, 19 years old, and it's too late. We need to have those discussions much earlier—12 years old. If the person with a disability has older siblings, we need to start even earlier, because the siblings are going to be talking about going to work. Mom and dad go to work, so there's an expectation that everybody who grows up goes to work. It should be the same for someone who has a disability. We have to change that mindset right from the get-go.

We need to have our agencies, we need to have our stakeholder groups, and we need to have families talking to a child so that when they grow up and they are ready, the expectation is that they will be in the workforce. If it doesn't work out, we'll deal with that when the time comes.

Last year, I was working on a federal task force, and I met with about 75 Canadian corporations. We talked to CEOs and heads of many large companies. They told us that they wanted to hire people with disabilities and they wanted to be inclusive, but they didn't know how, so we still have to make that connection with corporate Canada. That's not just for skilled labour. Corporate Canada also does, and can, hire people who have developmental disabilities.

I think my time is up in terms of speaking. I could pass that on to questions now.

The Chair (Mrs. Laura Albanese): Sure. Thank you. The question time will be starting. Each party will have 10 minutes to address the questions, and we will start with the Conservative Party. Ms. Jones?

Ms. Sylvia Jones: Thank you, Mr. Wafer. I'm really very pleased that you're able to come to the committee, because one of the things that we think is so important, in terms of recommendations going forward, is how do we incorporate that availability for jobs?

You started to talk about, before you timed out, the challenges when you spoke to corporate executives, corporate Canada. Can you expand on what you were hearing and what you were recommending from your experience?

Mr. Mark Wafer: Yes. The issue with corporate Canada—if you look at the number of people who are participating in the workforce today who have a disability, only 7% of those actually work for corporations; 93% work for small to medium-sized businesses. There are many reasons for that, but the most obvious reason is that Canadian corporations tend to buy into the myths and misperceptions a lot more than a small business will. A small business can make decisions very quickly, whereas if it's RBC or BMO or someone like that, it's like trying to turn the Titanic around every time we want to make a change.

But the CEOs get it. They don't always get it for the right reason, but they know that it's on their watch. An executive might get it; certainly, we need talent from the top. But in corporations, we have what we call the "permafrost," which are the middle managers, which make up 40,000 to 50,000 to 60,000 employees. They're the real issue. If you take the head of HR in a corporation, for example, the CEO will say to that head of HR, "Hire the best and the brightest, and don't let me down," and a week later, somebody comes in in a wheelchair who just happens to be the best person for that job, but the head of HR will be reminded of that conversation she had last week with the CEO. So it's going to be the toughest nut to crack: corporate Canada. That's why the focus right now with all of the agencies and stakeholder groups is with small to medium-sized businesses, because they know they can make a lot more success with that.

My phone doesn't stop ringing all day with stakeholder groups and families of people with disabilities looking for work for their child. Now, obviously, I'm more well-known in this than most, but it's constant. That doesn't happen in corporate Canada.

Ms. Sylvia Jones: You made no reference to any kind of incentive. Obviously, you're not getting incentives in your own business to do the hiring. Do you have a comment on whether there's a role for that, there's a value in that?

Mr. Mark Wafer: Yes, absolutely. I don't believe in incentives of any kind. The incentive, to me, is getting a great employee. My employees who have a disability, without question, are my best employees. I have a gentleman who has been with me 11 years who has two disabilities, one of them being schizophrenia. He is the only employee I have had in 20 years who has won the overall employee of the year twice. That's the value I have in my employee.

Businesses invest in an employee, just as you would invest in a piece of equipment for your business. You expect a return on that. When we have new employees, we send them for training, we send them to school; we send them to Tim Hortons University, for example. We expect a return on that. We're investing in our people.

If we take a subsidy—a wage subsidy, or whatever you want to call it—we're not investing in our person. Wage subsidies actually work against us. Now, there is a place for a wage subsidy, but it should be used only as a very, very last resort and only in a very small number of situations.

The business benefits of being an inclusive employer speak for themselves, so businesses don't need that additional \$200, \$300 or \$400 per week. It's not going to make any difference. But what will make a difference is, if an employer is taking a wage subsidy, they will look at that employee differently. Managers will look at that employee differently: "Let's not send them for training, because when the subsidy ends, we might be getting rid of them anyway."

The success rate of subsidies is extremely poor. I've hired nearly 100 people; I've never taken a wage subsidy. I don't see the point in it.

Ms. Sylvia Jones: Thank you. I'll let my colleagues ask.

Mrs. Christine Elliott: Thank you very much, Mark, for taking the time to be here. I think it's really important, what you have to say, because this is one of the biggest issues that we're facing: how to get people into employment so that they can also create those kinds of social networks that are so important to everyone.

Has that been your experience, that once you have someone with a disability that comes into your employment—can you tell us a little bit about how they relate to the other employees and what that does to their life in general?

Mr. Mark Wafer: Well, the first thing is that human beings tend to be hard-wired. I'm no different to anybody else. When I see a new employee who has a disability, I tend to do sort of a litmus test. I know exactly what that employee's capabilities are. I've hired almost 100 people with disabilities, and I'm happy to say that I was wrong nearly 100 times. The capacity of a person who has a disability, the capability, is always far greater than what we really think it is. So they bring something of huge value to the business.

For that reason, other employees tend to raise the bar, when they see that productivity levels have gone up, for example, because the people who have a disability, their productivity level is higher. By the way, that has happened very often. Safety ratings have increased in my business. So when we start to see people with disabilities setting the standard—for example, for uniform wear, I have one employee whose uniform is military crisp every time he comes to work, but the rest of them look like bums. He set the standard for uniform wear, and everybody else raises the bar.

1630

Being an inclusive employer has a profound effect on the rest of your employees. Forty-three of my employees today have a disability, but 210 of them don't, and so it has a profound effect on them.

I actually have people who contact me and say, "Are you the Tim Hortons franchisee who hires people with disabilities?" I say, "Yes, I am." They say, "Well, okay. I'd like to apply." I say, "Oh, you have a disability," and they say, "No, I don't." So it's quite profound. People want to be involved in an inclusive environment.

What it does is, it changes the culture of your workplace by being inclusive once you've built capacity with people with disabilities. Employees like it, and customers like it. In 20 years in business, I have never had a customer make a negative remark about any of the people we have working who have a disability.

My expectations of people with disabilities are exactly the same as everybody else in the business. They have a boss, they have a job to do, and I expect it to be done.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): You have about a minute.

Mrs. Christine Elliott: Okay. Well, I'll make it quick, then. What recommendation would you make to us about what we should say about the whole employability situation as part of our recommendations in this report?

Mr. Mark Wafer: I think there are two. One, I think government has to have an overall policy on disabilities in terms of work, because there's a lot of different messages that I hear from different facets of government and stakeholder groups and quasi-governmental agencies, such as social service agencies, across the province. I think there has to be an overall strategy. Of course, that's not my expertise, but I think that has to happen.

If we look at the fact that we've got wage subsidies now for people who don't have disabilities, where does that put people who have a disability? It's very hard for me to speak to a CEO and say, "You know what? There's some terrific business benefits to being an inclusive employer," and they say, "Well, why would I do that if I can get somebody else, and I could get paid for it, and they don't have a disability?" So that is actually working against us right now.

One of the most important things that we can do, and this is in the federal government—we have the Opportunities Fund, which in 2015 will be increased by another 33%. That type of funding, that type of money, can be used very well for employer engagement programs. Employer engagement is going to be one of the most important ways that we're going to educate the private sector.

Government can't solve this problem. We've tried for 50 years. Government can't solve this problem. Stakeholders can't solve this problem. Social service agencies can't solve this problem. Only the private sector can solve this problem because what we're trying to do is get people with disabilities into the private sector. Unless the private sector steps up and says, "We're going to do this," we're going to fail. We can shovel all kinds of money at the problem. We're going to have the same conversation 20 years from now if we don't have the private sector buy into this.

When I speak to a CEO as a business owner or I speak to a business group, there is never a time when I don't have some success where at least one person comes up to me and says, "I had no idea about this. Now that I'm aware of it, this makes total sense." So we're going to make change that way. We're not going to make change by creating more red tape, creating more legislation and policies and so forth.

AODA, for example is great piece of legislation, but when it comes to the integrated standard, part of which is employment, that's not going to move the needle. That brings much-needed awareness to the issue. That means that people with disabilities will get interviewed, but it's not going to move the needle in terms of how many people will find work until such time as we educate the private sector and show them the business benefits of being an inclusive employer.

Mrs. Christine Elliott: Thank you.

The Chair (Mrs. Laura Albanese): Ms. DiNovo.

Ms. Cheri DiNovo: Thank you very much for coming before us. I'm going to pick up where Ms. Elliott left off, really. When you think about and look at employer engagement programs, the kinds of things that you're suggesting that we should be encouraging, what would that look like? What can the government of Ontario do to bring about employer engagement programs? What would they look like?

Mr. Mark Wafer: Well, the government can certainly provide the funding for such events.

Ms. Cheri DiNovo: What would that funding go to? Where would it go?

Mr. Mark Wafer: Well, I'll give you an example. There's an agency in Ontario called the Ontario Disability Employment Network. It's just a small agency. I'm working with them to put together an employment engagement event for October of this year, and we're hoping to have 350 to 400 of Ontario's top companies there. We're talking about the big corporations and the small corporations as well.

We ran into a roadblock. We approached Service Canada and we ran into a major roadblock in trying to get seed money for this. ODEN is very small, but punches well above its weight. What we want to do is get 400 businesses into one room and talk to them about the business benefits, talk to them about how we can solve the looming labour shortage for them, how we can be a consultant to them for their business to make their business better. But we ran into a roadblock with Service Canada because they cannot provide us the seed money to do this. We needed \$50,000 just to advertise this properly in the Globe and Mail and in Canadian Business magazine and so on. We pushed it back. This is the type of thing that the government of Ontario can certainly be helping us with.

Three months ago, I was a keynote speaker at the Canadian Federation of Independent Grocers AGM in Toronto—660 of Canada's grocery heads across Canada in one room. I spoke for 45 minutes. Afterwards, I had a lineup that was an hour and 45 minutes long of grocery store owners saying, "I think you've just helped me solve my labour issue." Many of those were from Alberta and BC, where we're already seeing significant labour issues. So businesses really get it and they get it when the message is delivered from another business owner.

I see the government's role there in making sure that the funding is in place for those. The money is already there; we just need to spend it more wisely. We've got the federal-provincial transfer money, which is \$220-million-plus right now. Some of that money should be used for employee engagement. That's the way forward.

Ms. Cheri DiNovo: In some instances, depending on the disability that the person has, there's actually some kind of hard capital needed to change the workplace a little bit to accommodate people; let's put it that way. For example, we have a wonderful volunteer in our office; she's blind. There are many things she can help do and

there are many things she cannot help do because we don't have the wherewithal to translate all the paper we deal with into Braille etc. Would you see a role for some of this money to go towards corporations to do that? Again, we're looking for solutions here of how we can help more employers do the kind of employment you do.

Mr. Mark Wafer: Absolutely. Accommodations are an issue for some people. But if you look at the statistics, 65% of people with a disability, when they go into the workforce, do not need an accommodation at all; 35% need an accommodation which is going to have an average cost of \$500 or less, and that includes extra training. So if it's a person who has a developmental challenge, there will be extra training, training will take longer, that's included in that \$500. The number of people with a disability getting into the workforce who need a long-term accommodation, ongoing or expensive, is only 4%. So it's a very small number of people who are actually getting into the workforce.

The Opportunities Fund right now has provisions—and this is the federal Opportunities Fund—for helping businesses pay for some of those accommodation costs, but only a very small fraction of it. The vast amount of that fund is used for wage subsidies. In my opinion, that's a waste of money, because it's not sustainable. We're not building for the future. Where the provincial government can certainly step in is to provide funding for those accommodations.

Many corporations today, when it comes to accommodations, have created central accommodation programs. Deloitte, for example, has 57 offices across Canada. Deloitte has one central accommodation pool, so if Deloitte in Toronto, for example, hires people who might require a sit-stand desk, which is a \$12,000 piece of equipment, the Toronto location is not penalized in its profit and loss statement because the money comes from a centralized location. Businesses are already looking at that; businesses are already finding solutions to the accommodations. Absolutely, government can help with that.

1640

Ms. Cheri DiNovo: Okay, thank you. My colleague has questions, too.

Miss Monique Taylor: Thank you so much, first of all, for the work that you do, and the enrichment that I'm sure it brings to many lives. Having meaningful work, we've heard, is so important to so many young people and people with disabilities, so good job.

I was looking through this. I believe you brought this report. This panel—I haven't had a lot of chance—completely speaks to, or was made up of, businesses that are already doing this?

Mr. Mark Wafer: Are you talking about the people who created the panel?

Miss Monique Taylor: That's right.

Mr. Mark Wafer: Of the four members of the panel, three are in business and one is a stakeholder.

5 MARS 2014

Miss Monique Taylor: Right. But major banks, law firms on Bay Street, are they moving forward with this? Are they getting involved?

Mr. Mark Wafer: The companies that are listed in there are the companies that we consulted with. We consulted with 75 companies and we had 212 online submissions from companies. The results that you see in there are the results of our consultation with those companies.

Miss Monique Taylor: Okay.

Mr. Mark Wafer: They're in alphabetical order, not in order of how well they do in terms of hiring people with disabilities. I can tell you that every one of them sucks; they're awful. Corporations are really pathetic at hiring people with disabilities.

Miss Monique Taylor: Doing this research, do you find that it brought awareness to the situation and do you think it would make any changes?

Mr. Mark Wafer: Say again.

Miss Monique Taylor: Do you think the work that you did here, speaking to these corporations that were failing, has made a difference to make them think differently at all?

Mr. Mark Wafer: A huge difference—huge.

Miss Monique Taylor: It has? That's good.

Mr. Mark Wafer: Once you bring your awareness to a business, once you talk about it and you talk about the business benefits—because I didn't just consult with them. I gave them a 40-minute pep talk as well about what happens in my business and why they should be doing it, too. Quite a few of those companies that are in there, the people who I met with, we've actually become friends, because they use me as a consultant now to see how they can bring people with disabilities on board.

Miss Monique Taylor: That's really great. I know I was speaking with somebody in my community who had a part-time job somewhere and then that job was cancelled because of insurance costs. Have you had any of those issues where the insurance rates are higher because you have people with disabilities?

Mr. Mark Wafer: I can assure you that's false. It's absolutely false. If that was said, it's not true. Insurance cannot be increased because you hire people with disabilities. Insurance can only increase in a business because you have a poor safety record.

I've hired 100 people with disabilities in the last 20 years. I have never had a WSIB claim for any of the people I have with a disability—not one. I know exactly what the rest of them cost me. By looking at this from a safety point of view, you're at least as safe, but most likely, you have a safer workforce.

First of all, insurance companies can't discriminate, but they will never increase your insurance premiums because you've hired people with disabilities. That's a falsehood. It is, actually, a fear. It's one of the fears that I hear from CEOs, that their insurance costs will go up. It's not true at all.

Miss Monique Taylor: Great. Thank you so much.

Mr. Mark Wafer: Thank you.

The Chair (Mrs. Laura Albanese): Thank you. Ms. Hunter?

Ms. Mitzie Hunter: Mr. Wafer, thank you so much for joining us today and for the work that you do with people with disabilities in your franchises—and really, the examples that you're providing for other employers—because that's the way to build confidence amongst businesses, for them to see another businessman that is using this as a method of attracting great employees and showing them that they can do it as well.

I'm wondering, from your experience and from talking to other businesses, if there are specific types of businesses or types of companies that are well suited for employing people with disabilities; specifically, those with intellectual disabilities.

Mr. Mark Wafer: There is no sector and there is no business which will be better suited to hiring a person with a disability or a person who has an intellectual disability.

What we find, though, is that social service agencies tend to go for the low-hanging fruit, which would be my sector, the quick-service restaurant sector, because that's the easiest one: people with intellectual disabilities cleaning the dining room, doing the dishes at McDonald's and taking the garbage out, or looking after a parking lot. This is because agencies always tend to go for what's going to be easiest, and I think the last time I looked at the statistics, 68% of people with an intellectual disability who are in the workforce were working in the retail sector. That's not because the retail sector is better suited for them; it's simply because that's where they've been focused.

People with intellectual disabilities can work anywhere. Obviously, there's going to be a limit to what they can do, but each one is going to be limited based on their own capacity. If you don't give them a chance, you never know.

Like I said earlier, when we talk about corporate Canada, corporate Canada can hire people with intellectual disabilities; they just don't do it. There is no one sector which is better than the other.

Ms. Mitzie Hunter: In terms of better engaging employers and companies, demonstrating to them that there is an opportunity to engage this group of talented individuals, what would be some concrete things that, from your perspective, we could do to get them more involved?

Mr. Mark Wafer: In terms of engaging business?

Ms. Mitzie Hunter: Yes.

Mr. Mark Wafer: Well, the first one is, education is key. So education and awareness is going to be key. But if you go further than that, we're facing a looming labour shortage; no question about it. Last year, the Canadian Federation of Independent Business did a survey of its members and asked them, what is their number one business constraint today? Some 38% said skilled labour was the number one business constraint. Okay, we get that. We see what's happening out west. But 13% said that their number one business constraint today was a shortage of unskilled labour. If that's the case—and this

is 10 to 12 to 15 years before we're expecting that huge labour shortage to hit—this is a way to solve that issue with businesses. You've got 350,000 businesses in Canada that have hired at least one person in the last year. They are going to start to feel the crunch. People in Canada who have a disability are the answer to that issue.

Last year, the Prime Minister—he said this three times; the Prime Minister has said this three times—said that we're going to be a million workers short by between 2020 and 2025. It's going to affect our GDP by 1% to 1.5%.

At the same time, we have 800,000 Canadians today job-ready who are unemployed and have a disability, and 340,000 of them have a post-secondary education. We have that huge disconnect. So when we talk to businesses, those are the things that we talk about. It's not just about the obvious business benefits of hiring somebody with a disability. It's also about solving a huge issue with a labour shortage you're going to have very shortly.

Ms. Mitzie Hunter: Is there anything from an educational perspective that we can do better in transitioning into work? You mentioned that 300,000 of them have post-secondary, so what could we do to better—

Mr. Mark Wafer: Well, that's a whole other question, really. It's a very good question, Mitzie. We do have a very large population of students coming out of school—43,000 in post-secondary education in Ontario alone, going up 15% per year. This coming September, it's expected to go up 17%. We're one of the leaders in the world at getting people with disabilities through post-secondary education. The problem is when they graduate. Schools do a very good job—secondary schools and the universities do a very good job of accommodating students with disabilities.

1650

I spent a little bit of time at Algonquin College, and I was astounded at the number of students walking the halls and in wheelchairs: blind, deaf, all types of disabilities. It was really great to see. But what happens to those people when they graduate? We're not really doing very much in terms of readying them for the real world.

One of the things that we know for sure is that the greatest barometer of whether a person with a disability gets a job when they graduate is whether they had a job before they graduated. We're not looking at that; we're not working on that. Children who have disabilities don't have paper routes. They don't work at McDonald's or Tim Hortons. They don't have those jobs that increase their soft skills and their confidence so that they have something on their applications, they have something on their resumé when they graduate from university. The resumé is blank. Government can certainly help in that area, ensuring that teenagers in high school who have disabilities have an equal opportunity—because it's not a level playing field—of getting jobs during the summer.

Certainly, if we talk about wage subsidies of any kind, as loath as I am to accept those, wage subsidies probably would fit into the summer jobs program for children who

have disabilities. We really need to have them come out of university with something on their resumé and some understanding of what the soft skills are going to be, the expectation.

I met a gentleman just two years ago, so 2011, who had been called to the bar in 2004. He never worked. For seven years, he never worked. I helped him get into Deloitte as a lawyer, as corporate counsel. The chief corporate counsel said to me afterward, "He is a fantastic lawyer—fantastic. But his social skills and soft skills are so poor. We really need to work on that." He said, "If the universities had just done a better job, we would have been better off." He was a quick study, so today he is an awesome asset to Deloitte. But it is an issue, and in some cases, that person may have lost his job if he didn't have a more understanding boss.

Ms. Mitzie Hunter: Right. So we can't shift that on to employers. We have to support them all the way through.

Mr. Mark Wafer: Yes.

Ms. Mitzie Hunter: Thank you.

The Chair (Mrs. Laura Albanese): One minute left.

Ms. Soo Wong: One minute—quickly.

Thank you so much for your presentation today, Mr. Wafer. I noticed in your report, on page 24, the topic of partnering with educational institutions. I just heard you talking about increasing the soft skills so that the young person can be successful. Can you elaborate a little bit more? Currently, what more should the institution, both high school and post-secondary, do to support the young person when it comes to the issue of soft skills?

Mr. Mark Wafer: Well, the focus right now is on readying them to have the skills to actually do the job. Take a look at community college, for example. The last six months of community college quite often are in the workplace. It's a co-op program, and then you graduate, and quite often you end up working in the place where you did your co-op. I remember 30 years ago, I did that. But that's not happening for people who have disabilities. They're not having opportunities to be in co-op programs.

One of my stores has a co-op student every year, and the difference in that person's confidence and capabilities over that year of them working in my store is just enormous. I'm talking about somebody with a profound intellectual disability. When they graduate, they're ready for the workplace.

There are many, many areas where we can work on soft skills. But the only way that you can really improve on social skills, understanding how to communicate with other people your age or communicate with the opposite sex, for example, is by actually doing it. When we take those opportunities away from people with disabilities, they regress.

I'll give you the example of myself. I have a hearing problem; I'm deaf. When I was a student in school, I was excluded from a lot of things, and it was foolishness. I was capable of doing all of the things I was excluded from, but it was because people thought better. They thought, "Oh, well, Mark will get hurt if he plays

soccer.” It was very foolish. That mindset is still there today.

So it’s not just getting them through the curriculum and getting them ready for the workforce; it’s making sure that they take part in all of the other things as well.

One of the first people I found work for when I started this one program was a man with cerebral palsy who was an advertising student. He graduated from Durham College in advertising. I got him a job in a car dealership, and he was doing some good work. Then I went by to see how he was doing, how it was going, and I noticed he was eating a sandwich at his desk while everybody else was on the second floor having their lunch. I said, “This is not right,” because he’s missing out on all of that social interaction. That’s how soft skills are developed: not by doing your work, and not by being great at your job, but by being where everybody else is. Coming through school, you’ve got to do the same thing.

Ms. Soo Wong: Thank you very, very much for your presentation. I think you have provided some very concrete and realistic recommendations and suggestions for the committee. I want to say thank you for your leadership and your vision, because you have mentored thousands of others out there, so we really appreciate it.

Mr. Mark Wafer: Thank you very much.

The Chair (Mrs. Laura Albanese): I too would like to thank you for your presentation to the committee this afternoon. It has been a very valuable learning experience listening to all that you have done. Congratulations.

Mr. Mark Wafer: Thank you very much for having me.

The Chair (Mrs. Laura Albanese): That concludes that part of the meeting this afternoon. Does the committee wish to go in camera to begin discussing, perhaps,

some of the report writing? Or is there other business that we want to conduct before that?

Mrs. Christine Elliott: I just have a brief comment that there was a whole CBC The National segment on Mark and speaking to some of his employees that aired last week. I think we’re trying to send the link around to everybody to take a look at it, just to see from the perspective of his employees how things are going. So, if you’re interested, we’ll make sure that you—

The Clerk of the Committee (Mr. Trevor Day): Ms. Elliott sent it to us prior to this. I apologize; it didn’t get out to the committee members, but it should have. It is a very good piece. It does sort of capture the basis of the presentation, so we’ll have that out immediately.

The Chair (Mrs. Laura Albanese): That’s much appreciated. Any further comments before we go in camera?

So just a couple of minutes requested by the Clerk—

Ms. Cheri DiNovo: Chair?

The Chair (Mrs. Laura Albanese): Yes, Ms. DiNovo.

Ms. Cheri DiNovo: I had given Trevor the group Keys to Inclusion. I think I raised this last time. This is not a group that necessarily wants to present, but it is a group that would like to play for us, perform for us, at some point. I’m just wondering if there’s going to be an opportunity in this entire process where we can get back to them and ask them to come and perform.

The Chair (Mrs. Laura Albanese): Well, it’s something that we can discuss as a committee.

The Clerk will need a couple of minutes to get set up, and then we’ll get back to the table.

The committee continued in closed session at 1658.

CONTENTS

Wednesday 5 March 2014

Developmental services strategy	DS-573
Mr. Mark Wafer	DS-573

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

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2
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DS-1

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Journal des débats (Hansard)

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Select Committee on Developmental Services

Developmental services strategy

Comité spécial des services aux personnes ayant une déficience intellectuelle

Stratégie de services
aux personnes ayant
une déficience intellectuelle



Chair: Laura Albanese
Clerk: Trevor Day

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

SELECT COMMITTEE ON
DEVELOPMENTAL SERVICESCOMITÉ SPÉCIAL DES SERVICES
AUX PERSONNES AYANT
UNE DÉFICIENCE INTELLECTUELLE

Monday 21 July 2014

Lundi 21 juillet 2014

The committee met at 0907 in committee room 1.

DEVELOPMENTAL SERVICES STRATEGY

The Chair (Mrs. Laura Albanese): I call the Select Committee on Developmental Services to order. I want to start by saying how pleased I am that we are here today to adopt, or readopt, our report. We had made a commitment, as members, before the House dissolved that whomever was re-elected would work hard to revive this committee, and I think we've all put our best efforts forward to do that. That's what brings us here today.

So we are here. We have less than one hour before us to get our work done. I know that these recommendations in our report will make a difference in the lives of many people. That's why we wanted to do this as quickly as possible.

We'll get down to business.

Interjection.

The Chair (Mrs. Laura Albanese): We have a couple of questions. I would like to allow each party to say a few words, if they wish, before we get down to the adoption. Ms. Jones.

Ms. Sylvia Jones: Chair, I echo your comments. I think it's very important for the families and the individuals who serve people with a developmental disability that we proceed with this report. I will only slightly modify it and say that I believe this report is a great opportunity and will make a difference, if adopted.

My process question relates to whether this will be part of routine proceedings where you, as the Chair, present?

The Chair (Mrs. Laura Albanese): Yes.

Ms. Sylvia Jones: Okay. Thank you.

The Chair (Mrs. Laura Albanese): Any comments?

Miss Monique Taylor: Thank you, Chair. I'm just relieved about the fact that we've been brought back together again and that the people of this province will see the report that we worked so hard on to make sure that we're making a difference in people's lives.

I'm hopeful that the recommendations will be utilized, that they will make a difference, and that we will move people out of crisis in this province into a better future. That's definitely my goal and my intentions of being on this committee and the hopes that I see coming from today's report.

The Chair (Mrs. Laura Albanese): Thank you. Any comments? Ms. Wong.

Ms. Soo Wong: I also want to echo what my colleagues said, but I think the bigger piece about this report—wearing my other hat in my previous life as a registered nurse—is that this report, unlike others, has a following through the standing committee; because often we see how many reports come from this Legislature, and there's no follow-up. I'm very pleased that right in the recommendation, clearly stated, is the timeline and the expectations for the various ministries, but more importantly, that they will be reporting back to the House and that there will be a standing committee monitoring and tracking the outcome, because Ontarians expect us to deliver but, more importantly, the families and the individuals who presented to this committee expect us to deliver.

I'm very pleased to have a recommendation that includes those pieces because I certainly do not want this to be lost in our busy lives.

The Chair (Mrs. Laura Albanese): Thank you. We just have a few routine questions here. First of all, shall the report be adopted? Yes.

Shall it be printed and translated? Yes.

Shall it be presented and moved for adoption of recommendations? Yes.

Shall we request a comprehensive response? Yes.

Once translated and printed, a bilingual coloured copy will be tabled with the Clerk? Yes. So everything is done.

Any further comments? Ms. Elliott.

Ms. Christine Elliott: I would like to thank the legislative research team, both Erica and Heather, for all of your work on this. I don't think we would have had nearly as good a product without all of your hard work and diligence, so I just want, on behalf of the whole committee, to thank you very much. You played a huge part in this.

Applause.

The Chair (Mrs. Laura Albanese): Miss Taylor.

Miss Monique Taylor: Chair, I was just wondering if the committee wanted to do a press or media release combination, doing something out together, some kind of stand-up or something on the presentation of this report.

The Chair (Mrs. Laura Albanese): It depends on the will of the committee. Everybody's in agreement?

The Clerk of the Committee (Mr. Trevor Day): How, when, where?

Interjection: What exactly?

The Chair (Mrs. Laura Albanese): What exactly?

The Clerk of the Committee (Mr. Trevor Day): We're going to need some details.

The Chair (Mrs. Laura Albanese): We'll need some details on that.

The Clerk of the Committee (Mr. Trevor Day): Like, here, now.

The Chair (Mrs. Laura Albanese): Here, now, details. Would we want to issue a press release—well, it will be tabled tomorrow, so it could be done in tandem with that after we table—or in the morning, I guess, would be better. We can issue a press release in the morning saying, "Today, the report will be tabled."

Ms. Sylvia Jones: A quick process question: To that end, the report actually doesn't become public until it is tabled?

The Clerk of the Committee (Mr. Trevor Day): That's correct.

Ms. Sylvia Jones: Okay. Thank you.

Interjection: So the press release has to come up right after it's tabled.

The Chair (Mrs. Laura Albanese): Would the legislative research team draft it, and perhaps after you've drafted it, show it to—

Interjection: Subcommittee?

The Chair (Mrs. Laura Albanese): Yes, subcommittee members.

The Clerk of the Committee (Mr. Trevor Day): Technically, we don't have a subcommittee.

The Chair (Mrs. Laura Albanese): Technically, we do not have a subcommittee.

The Clerk of the Committee (Mr. Trevor Day): I'm going to need a motion appointing a subcommittee, if that's the case.

Ms. Jones?

Ms. Sylvia Jones: So the motion would read, "A subcommittee of Ms. Elliott, Miss Taylor and Ms. Wong, along with the Chair."

The Chair (Mrs. Laura Albanese): Agreed? Agreed.

Ms. Wong, did you want to ask a question?

Ms. Soo Wong: No, I was just checking about the proceeding for tomorrow. Trevor, can you just clarify? The House doesn't start in the afternoon till 3. Are we moving that up? Because if I heard correctly, until it gets presented to the House, it's not a public report—

The Clerk of the Committee (Mr. Trevor Day): That's correct.

Ms. Soo Wong: —so we can't do anything till after 3.

The Clerk of the Committee (Mr. Trevor Day): That's right.

Ms. Soo Wong: So probably 4 o'clock, when all the—

The Chair (Mrs. Laura Albanese): You can send a press release just saying that it will be tabled at 3 p.m.

You have to be vague about the content; obviously you can't reveal the content of the ramifications.

The Clerk of the Committee (Mr. Trevor Day): Do you want the—one, a member has to book the media studio, and we can do that through the Chair—

The Chair (Mrs. Laura Albanese): Issuing a press release doesn't mean booking the media studio. They're two distinct—

The Clerk of the Committee (Mr. Trevor Day): Okay. What exactly do you want to happen?

The Chair (Mrs. Laura Albanese): I would say a press release going out to all major outlets would be sufficient. If they're interested, they will come to us for interviews.

The Clerk of the Committee (Mr. Trevor Day): Okay. And is this before or after the tabling of the report in the House?

Ms. Sylvia Jones: I think you have to do it after, because you want to put the report with it. Right?

The Clerk of the Committee (Mr. Trevor Day): Okay, so we're going to do it after.

Miss Monique Taylor: So as soon as it's tabled, it can be sent—

Interjection: Exactly. Yes.

The Chair (Mrs. Laura Albanese): So it can be sent as an attachment.

The Clerk of the Committee (Mr. Trevor Day): An attachment to the press release. Okay.

What's going to happen is research is going to draft something up. The subcommittee will take a look, agree on it and then tomorrow, once we've tabled it in the House, it will get sent out with the report attached. Everyone's good with that?

Anything I haven't thought of can be determined by the subcommittee and/or the Chair.

Miss Monique Taylor: Breakfast.

The Clerk of the Committee (Mr. Trevor Day): We're never meeting. We're not meeting anymore. That's it.

The Chair (Mrs. Laura Albanese): Well, I want to thank all of you, all of the members. I know you have put your heart into this.

I want to thank the Clerk. I want to thank the legislative research team that has put in so much time and effort, and Hansard as well, and all the people who travelled with us throughout Ontario, and everyone who has presented, from the ministries to the families to the caregivers.

As I said at the beginning, I really do hope that the recommendations contained in this report will make a difference in people's lives sooner rather than later.

Thank you to all of you. Thank you to my Vice-Chair, who has been of great assistance. Well done. Well done, to everyone.

We're adjourned.

The committee adjourned at 0917.

CONTENTS

Monday 21 July 2014

Developmental services strategy	DS-1
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3 1761 1146608 4

